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VRIJE UNIVERSITEIT

Who Do You Say That I Am?

Overcoming the Marginalization of Persons with Intellectual and Developmental Disabilities
in the US Catholic Church

ACADEMISCH PROEFSCHRIFT

ter verkrijging van de graad Doctor of Philosophy aan
de Vrije Universiteit Amsterdam,
op gezag van de rector magnificus
prof.dr. V. Subramaniam,
in het openbaar te verdedigen
ten overstaan van de promotiecommissie
van de Faculteit Religie en Theologie
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door

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geboren te Massachusetts, Verenigde Staten

promotoren:

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prof.dr. T.E. Reynolds

Summary

Why do individuals with intellectual and developmental disabilities (IDD) continue to struggle to participate in the life of the Catholic Church in an 'ordinary way,' rather than via 'special' programs and activities? Too often participation is defined based on stereotypes, diagnostic labels, and identified 'deficits,' rather than on interests, abilities, and possibilities. Such practice contradicts the principles proclaimed within the *US Catholic Bishops Pastoral Statement on Persons with Disabilities*, which is grounded in Catholic Social Teaching, the object of which is the flourishing of all people. This is based on the innate dignity of every person who is created in the image of God and the call for all in the Church to live out the foundational commandment to love God and love their neighbor as themselves. Catholic Social Teaching provides the theological framework for my thesis that proceeds in three stages.

Stage One: Chapters One through Four

The first stage explores history to discern trends that could explain the rupture between theology and pastoral practice concerning individuals with IDD. I develop my answer to the problem through posing the titular question to the Church on behalf of individuals with IDD. This recalls Jesus' question to the disciples and consequent silencing when he realizes they do not understand what he means. Narrative construction is an important part of comprehending and responding to the problem as learned through my historical exploration. I begin with the early development of organized ministry in the US Church and the development of the *US Pastoral Statement*, which is the US Church's elemental statement on the intersection of belief, disability and pastoral practice that was promulgated in 1978. Both the ministry and the statement are predicated on the outcomes of Vatican II.

Two important issues surface in this study. First I discover a meta-narrative woven throughout the *US Pastoral Statement* and activities of organized ministry with persons with disabilities that is contrary to the principles of the Gospel, dimming its light. Because of this I name it the *shadow narrative*. It consists of five different threads, each their own narrative, though sometimes combined. Examples from Vatican and papal

documents are also noted. Two of the threads are particularly problematic because of their popularity and the way that they diminish individuals with disabilities as persons of interest in their own right. They are patronizing, sentimental and reflect all that is maligned about charity today.

These threads have deep historical roots and are embedded in society's subconscious, which leads to the second discovery. Entrenched in the past, the *shadow narrative* also hides the implications of the *growing end of human dignity* that was proclaimed essential to Catholic social doctrine in the Second Vatican Council and provides the seeds for the *US Pastoral Statement*. I draw from Henri Nouwen's acclaimed *Adam: God's Beloved* to illustrate the strong sentimentality that permeates narratives about persons with IDD. The different threads of the *shadow narrative* have been operative throughout human history reinforcing structures of power and marginalization. Tom Reynolds work on the "cult of normalcy" is particularly helpful for this discussion about creating a space that is often sentimentally referred to as "on the margins," where Jesus can be found.

An important thread in the *shadow narrative* is that of charity, which is often named in responding to individuals with IDD, but in patronizing, rather than helpful, ways. Further historical investigation into the development of charity seeks to understand what has happened to the call to love ones neighbor as oneself, which is supposed to be at the heart of charity. Beginning with its Judeo-Christian roots studying into the Middle Ages discovers cultural insertions which possibly forecast the problems identified with charity today. Jewish and Christian charitable activity evolve in the fourth century in ways which consolidate ecclesial power on a different tangent from the early monastic tradition that was occurring around the same time. It too, however, goes through an upheaval during the Carolingian dynasty. I draw heavily on Pope Benedict XVI's encyclical, *Caritas in Veritate*, and Hans Reinders' reflections on charity to challenge its current fractured state and wonder how it might be restored.

Stage Two: Chapter Five

The second stage flips my opening question and I pivot attention from persons with IDD to the Church and its self-understanding as the body of Christ, "Who do we say

we are?" The body of Christ is a strong metaphor for the Church, but on closer examination, it seems clear that this, like charity, has picked up attachments along the way that are contrary to Paul's intentions for the Church in Corinth. Drawing particularly on Brian Brock, Gordon Fee, and Jerome Murphy-O'Connor, I explore hermeneutical sources on 1Cor 12, particularly concerning three issues: individual gifts vs. manifestations of the Spirit, unity in diversity vs. diversity in unity, and who are the "weak"? This study provides unexpected insights into developments of the charity tradition during the Patristic era. It also yields a sense of the body of Christ that is much freer and open to diversity than is often understood with the typical focus on individual gifts, rather than a diverse whole that remains open to new possibilities through unfolding manifestations of the Spirit. Reynolds provides a provocative metaphor for the manifestations of the Spirit in the language of jazz, a call and response that is ever open to innovative potentialities. Though it is an important pivot point in the discussion, this chapter provides the theological framework for the project's constructive response. It provides the theological framework for understanding the church as the body of Christ.

Stage Three: Chapters Six through Eight

The final stage proposes a threefold answer to the problem named at the outset in which Social Role Valorization (SRV) is employed as a practical guide in this theological research. First SRV serves as a framework to understand how the *shadow narrative* has operated within the Church regarding individuals with IDD, socially and culturally.

Second, SRV is employed as a framework to counteract the devaluation and marginalization of these people in the church, in line with the original Pastoral Statement's commitment. In the background of this document is the influence of SRV's spiritual father, Wolf Wolfensberger, who, because of his Catholic background, regularly wrote about the marginalization of people with intellectual disabilities and developmental disabilities in the American Catholic Church. His work has undeniably inspired the prophetic vision of the bishops. Based on the principles of SRV, a seven-step plan for reforming the Church is being unfolded, requiring the commitment of clergy, religious and pastoral leaders, and the "person in the pew.."

Third, to answer the opening question of this thesis, “Who do you say that I am?” the theory and practice of *SRV* is linked to the need for a theological anthropology based on an understanding of Creation in which the diversity of human beings is honored. Useful sources for this is found in the work of Karl Rahner and Mary Doak who advocate embracing the differences within the human family rather than erasing them. The study concludes with a plea to rediscover the founding principles of Catholic Social Teaching.

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My work, and hence this project, presumes that Catholic theology provides all the validation to support full meaningful participation of individuals with intellectual and developmental disabilities in the life of the Church. It is framed within Catholic Social Teaching. Therefore, most of my sources are Catholic, but that does not intend any slight for the many esteemed voices in the discourse at the intersection of theology and disability, nor their influence on my thinking. It is such a gift that they are also the faculty for the Institute on Theology and Disability, which has provided critical opportunities for bringing together the many voices to wrestle with the tensions in this area.

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discovering possible sources for charity's misappropriation. My thanks and prayers are with Fr. Gabriel, who himself is a scholar of historical influences in development of Catholic liturgy.

In some ways, Jan's generous sharing of access to history of the ministry made my task much harder, because there was so much fascinating information! I really had to contain my focus (not always my strength!) to the ecclesial documents, with just enough of the ministry activity for analysis. The latter was particularly difficult, and I had a huge struggle organizing chapter two on the US Catholic Church. I am so thankful to Mary Beth Walsh for reading the chapter multiple times and for her guidelines for discernment. Mary Beth is also a valued friend and colleague who I met in my first month in this work. She is a theologian, a peer counselor on a hotline for parents of individuals with disabilities and the mother of two young men, Ben, who has autism and you will meet in these pages and Sean. As a member of the ministry's Executive Advisory Board, she has provided invaluable guidance on the important issues facing families living with autism and other disabilities and helping me to reach more parents.

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Ecclesial Documents

Pope John XXIII

Pacem in Terris, Peace on Earth.

1963

Vatican II

Dignitatis Humanae, Declaration on Religious Liberty

December 7, 1965

Apostolicam Actuositatem, Decree on the Apostolate of the Laity

November 18, 1965

Presbyterorum Ordinis, Decree on the Ministry and Life of Priests

December 7, 1965

Lumen Gentium, Dogmatic Constitution on the Church

November 21, 1964

Gaudium et Spes, Pastoral Constitution on the Church

in the Modern World

December 7, 1965

Pope Paul VI

Evangelii Nuntiandi, Proclaiming the Gospel.

1975

Pope John Paul II

Laborem Exercens, Through Work

Encyclical for 90th Anniversary for *Rerum Novarum*

1981

Homily, Jubilee of the Disabled

2000

Message of John Paul II on the Occasion of the International Symposium

on the Dignity and Rights of the Mentally Disabled Person

2004

Mane Nobiscum Domine, Stay with Us Lord

Apostolic Letter for the Year of the Eucharist,

2004

Pope Benedict XVI

Caritas in Veritate, Charity in Truth

2009

Pope Francis

Amoris Laetitia, The Joy of Love

2016

Laudato Si, On Care for Our Common Home

2015

Bull of Indiction of the Extraordinary Jubilee of Mercy

Misericordiae Vultus, Looking for Mercy

2015

Evangelii Gaudium, Joy of the Gospel

2013

Gaudete Et Exsultate, Rejoice and Be Glad

2018

U.S. Conference of Catholic Bishops

<i>Pastoral Statement of the U.S. Catholic Bishops on Persons with Disabilities</i>	1978
<i>Economic Justice for All: Catholic Social Teaching and the U.S. Economy</i>	1986
<i>A Century of Social Change: A Common Heritage, a Continuing Challenge</i>	1990
<i>Guidelines for Celebration of the Sacraments with Persons with Disabilities</i>	1995
<i>Sharing Catholic Social Teaching: Challenges and Directions</i>	1998
<i>National Directory for Catechesis</i>	2005
<i>Guidelines for Celebration of the Sacraments with Persons with Disabilities: Revised Edition</i>	2017
<i>Compendium of the Social Doctrine of the Church</i> Pontifical Council for Justice and Peace	2004
<i>Directory for Catechesis</i> Pontifical Council for the Promotion of the New Evangelization	2020

I. Introduction to the Problem

If bars are more accessible than altars;

If theaters are more welcoming than churches;

*If the publishers of "Readers Digest" are more concerned
about access to their message than those who print our religious books;*

*If the producers of PBS television programs are more sophisticated
about audio-description for those who are visually impaired and
captioning for those who are hard of hearing than those who plan our
liturgical celebrations;*

*Then we are failing to meet Christ's demand that we share the Good
News.*

~ Mary Jane Owen, 1992¹

A. *Rupture Between Theology and Pastoral Practice*

Why do individuals with intellectual and developmental disabilities (IDD) continue to struggle to participate in the life of the US Catholic Church in an 'ordinary way,' despite its contradiction to principles of Catholic Social Teaching that demands respect for human dignity and it's consequential possibility to flourish to one's capacity and live a fully human life? This is the research question this thesis seeks to address. Organized ministry with persons with IDD began nearly 60 years ago at the national level in the US Catholic Church. Yet the rupture between professed Church teaching and the lived experiences of individuals with IDD in the US Catholic Church continues to exist. They are very often ignored or restricted to stereotypic roles based on diagnostic labels and what they cannot do, rather than their interests and strengths? This clearly affronts their dignity as human beings. This glaring lack of unity between faith and practice within the Catholic Church, specifically regarding individuals with IDD, is the problem I seek to address.

¹ NCPD Archives, "Executive Board and Board of Directors Meeting Notes," pp. 1-2. Mary Jane Owen, NCPD Executive Director, "Report of the Executive Director," October 11, 1992.

Pope Francis noted this concern in 2016 during a catechetical conference in Rome.² Long standing stereotypes of dependency, sentimentality, or otherness contribute to this conundrum. A notable example of this are the Night to Shine proms sponsored by the Tim Tebow Foundation. Tim Tebow, founder of the organization which promotes the events found his purpose beyond playing sports, "to fight for people who can't fight for themselves."³ This is a noble mission for sure and seemingly very generous to make every person there king and queen for the night. While accepting statements of good intentions at face value, their effect is to perpetuate the marginalization of individuals with disabilities and restrict opportunities to develop and participate within ordinary community life and events. Rather than uplifting, many individuals with disabilities and their advocates report that events like the proms are dehumanizing and they feel used as objects of pity and opportunities for charity.⁴

There are admittedly mixed opinions on events like the Night to Shine proms. The Pontifical University Regina Apostolorum hosted one February 4, 2020. Attendees interviewed in the article reported having a good time. But what about the next day, and the next? Giving someone a wonderful night makes good memories, but how do they feel about the rest of their life? Why not put the significant resources of the Tim Tebow

² Pope Francis, "Address for the 25th Anniversary of the Concillio Episcopale Italiana: Disability Ministry and Catechesis," in *Toscana Oggi.it* (Rome 2016).

³ Claire Giangrave, "Tim Tebow and the Vatican Join Forces to Give Disabled an Epic Prom Night," *CNA*, 2/7 2020.

⁴ Elsa to All Abilities. Limitless Possibilities., undated, <https://blog.easterseals.com/what-message-do-tim-tebows-special-needs-proms-really-send/>; Ariel Henley, 2/28/2018, 2018, Having a prom for disabled people only is just as bad as 'separate but equal.', https://www.vice.com/en_us/article/7x7myx/prom-for-disabled-people-perpetuates-stigma; Patricia A Dunn and Jacob Stratman, "Disabling Assumptions: Overcoming": Analyzing Motivations in Shark Girl and the Running Dream," *The English Journal* 104, no. 4 (2015); Cassandra J. Davis and Jolene M. Thibedeau Boyd, "Stop Making It Weird: Why I'm Not Clapping," *Journal of Vocational Rehabilitation* 46 (2017); Jolene M Thibedeau Boyd and Cassandra J Beckman, "Stop Making It Weird 2.0: Imagining a Less-Weird World," *ibid.* 50, no. 3 (2019).

Foundation toward making a lasting difference in people's lives, by increasing access to the supports necessary to engage meaningfully in human society?

Perhaps looking deeper into Catholic Tradition will provide some helpful insights. However, if everything rests on human dignity, I should first clarify my use of the reference and its meaning within Catholic Social Teaching. Human dignity, it says, is founded on the reflection of God within every person, who is created in God's image. In fact, their very existence is "*willed*" by God and animated into life by God's breath.⁵ Therefore, every person, who is an inseparable union of spirit and matter consisting of one nature, "shares in the dignity of 'the image of God' which is infused throughout each person."⁶ Merriam-Webster dictionary provides two definitions. The first defines is as presenting oneself seriously, in control of oneself. The second states that dignity is the "quality of being worthy of honor or respect."⁷ This latter meaning is the correct understanding within Catholic Social Teaching and how I use it as well. Therefore, respecting human dignity dictates expectations of what is due to a person. More will be said about this in further discussions on Catholic Social Teaching and the Second Vatican Council.

Before going further, I will also clarify the term 'ordinary way.' Again, looking at the dictionary, for my purposes, the word ordinary is an adjective that refers to something done "in the normal order of events."⁸ Routine and usual are good synonyms for ordinary. Within the context of my question, I am asking why individuals with IDD do not participate in the life of the US Catholic Church in the usual ways of participation? Why do Catholic parishes typically set up 'special programs' or separate systems for

⁵ Catholic Church, *Catechism of the Catholic Church*, Second ed. (Citta del Vaticano: Libreria Editrice Vaticana, 1997), par 362.

⁶ Ibid., par 365, 364.

⁷ Merriam-Webster.com Dictionary, s.v. "dignity," accessed September 5, 2020, <https://www.merriam-webster.com/dictionary/dignity>.

⁸ Merriam-Webster.com Dictionary, s.v. "ordinary," accessed September 2, 2020, <https://www.merriam-webster.com/dictionary/ordinary>.

individuals with IDD? The next section will consider the necessary connection between the implications of this and pastoral practice or said another way, the relationship between belief and practice.

B. Lex Credendi, Lex Agendi

The Catholic Church has a strong theological tradition that affirms the inherent dignity of every person, regardless of ability or disability, and that all baptized persons share the same divine calling.⁹ However, its pastoral practices often do not reflect this, nor the Church's promise at baptism to support each person living out their baptismal vocation.¹⁰ Phone calls to parish offices from parents of individuals with disabilities may go unreturned, or when returned they are encouraged to either prepare their children for the sacraments at home, enroll them in separate programs, or even suggest there is no need as they are 'God's special angels.' By the time their sons and daughters are adults, the Church is at best absent in their life and at worst, a source of anxiety.

Belief informs practice and practice reveals belief. If the two are consistent with each other, there should be a circular relationship between them. When their relationship is ruptured, this integrity is lost. Instead, practice either reveals or generates a new set of beliefs. The call for consistency between theology and practice is not new. *Lex orandi lex credendi*, "the law of prayer [is] the law of belief," dates back to the patristic era as the Church was struggling through different interpretations of faith, in this case, the semi-Pelagian heresy.¹¹ In *Context and Text: Method in Liturgical Theology*, Kevin Irwin explores how the early Church dealt with the controversies of the day. Liturgical conformity to apostolic tradition was important, but this was not marked by textual or ritual rigidity. Irwin says that change, evolution and development were not only

⁹ USCCB, "Guidelines for Celebration of the Sacraments with Persons with Disabilities Revised Edition," (Washington, DC: USCCB, 2017), par 1.

¹⁰ Catholic Church, "The Rites of the Catholic Church," (Collegeville, MN: Liturgical Press, 1990), Introduction.

¹¹ Kevin W Irwin, *Context and Text: A Method for Liturgical Theology* (Collegeville, MN: Liturgical Press, 1994), p. 7.

possible, but were the norm, in a living theology that was expected to generate a response in Christian life.¹² My intention is not to trace the tradition of *lex orandi lex credendi* throughout the Church, but only to note that theological wrestling over the connection between prayer, belief and Christian life is not new.

Gerald O'Collins discusses three styles of contemporary theology in 1993 that I think frames the next discussion on *Catholic Social Teaching* well. He names them North Atlantic Theology, Liberation Theology and Liturgical Theology.¹³ O'Collins analyzes each according to its theological context, focus, orientation and expression of Christian faith. North Atlantic style is based in academia, focuses on truth that is rooted in the past and is expressed through knowledge, *lex credendi*. The style of Liberation Theology, he says, is located within life situations, particularly wherever marginalized people are; it focuses on justice in the present and is expressed through action, *lex agendi*. Liturgical Theology style takes place within liturgy, "the Church at prayer," with an emphasis on eastern mysticism; focuses on divine beauty, looking towards the future and is expressed through prayer, *lex orandi*. Taken together, the three styles could be said to describe the outline of Catholic Social Teaching to live an authentic Christian life, *lex credendi*, *lex agenda*, *lex orandi*, our past, present actions and the future, each held in tension together, not one over the other.

C. *Catholic Social Teaching*

The different styles of theology outlined in the last section indicate how different contexts and understandings of the same source yield different landscapes of faith. While this can and often does cause conflicts, Catholic Tradition is a living conversation

¹² Ibid., pp. 3-10.

¹³ Gerald O'Collins, *Retrieving Fundamental Theology: The Three Styles of Contemporary Theology* (Mahwah, NJ: Paulist Press, 1993), Source for this material is class discussion: "Foundations of Theology," taught by Richard R. Gaillardetz, PHD. Boston College Institute of Religious Education and Pastoral Ministry, Summer 2003.

between scripture and the ongoing life of the Church.¹⁴ The canonical texts of the Bible informs this conversation, but Tradition keeps faith relevant by engaging it with the changing contexts of life, through what John Courtney Murray referred to as the growing end of tradition.¹⁵ Murray discusses the particularly relevant papal statements to support this point at Vatican II in *The Problem of Religious Freedom*: Pope Leo XIII's encyclical, *Rerum Novarum* (1891), Pope Pius XII in *Divini Redemptoris* (1937), His Radio Message December 24, 1944, and Pope John XXIII in *Pacem in Terris* (1963).¹⁶ Catholic Social Teaching articulates this growing end within the Church's social doctrine that continues to be refined in subsequent papal statements

Catholic Social Teaching proclaims the Church's collective responsibility in the world to support human flourishing, by working to eliminate the existence and effects of poverty and injustice. Every person should have access to the basic things required for a truly human life: food, clothing, a home, medical care, education, employment, privacy, and respect. This grows out of the understanding of God's essential nature of love and communion, which also indicates the essential nature of the human person. As noted a few pages earlier, respect for human dignity states what is due to a person, such as the items listed above, and the implications of their innately social nature, that "if they do not enter into relationships with others they can neither live nor develop their

¹⁴ Richard R Gaillardetz, *By What Authority?: A Primer on Scripture, the Magisterium, and the Sense of the Faithful* (Liturgical Press, 2003), pp. 41-53.

¹⁵ John Courtney Murray, *The Problem of Religious Freedom* (Newman Press, 1965), pp. 58-64.

¹⁶ Ibid.

gifts.”¹⁷ Papal encyclicals, letters, and statements of bishop conferences develop it further based on the changing needs of human society, thereby maintaining its relevancy.¹⁸

The three organizational principles of Catholic Social Teaching call for concern for the common good; solidarity, which is feeling the experiences of others as one’s own; and subsidiarity, which is empowering growth and development through participation, rather than dependency. The move beyond dependency that Catholic Social Teaching promotes acknowledges the interdependent and social nature of human beings, rather than individualism and independent autonomy. Because of this social nature, living a human life means participating in family, social and political life, having relationships, as well as exercising rights and responsibilities within these arenas.¹⁹ Despite the decades long history of Catholic Social Teaching, the Church

¹⁷ Council Fathers of Vatican II, "Pastoral Constitution on the Church in the Modern World (*Gaudium Et Spes*)," ed. Austin Flannery, trans. Ambrose McNicholl, OP, Paul Lennon, OCarm, and Austin Flannery, OP, Kindle ed., *Vatican Council II: Constitutions, Decrees, Declarations: The Basic Sixteen Documents. A Completely Revised Translation in Inclusive Language* (Collegeville, MN: Liturgical Press, 1996; repr., 2014). par 12; Pontifical Council for Justice and Peace, "Compendium of the Social Doctrine of the Church," (Washington, DC: Libreria Editrice Vaticana, 2004; reprint, 2005), par 34-37.

¹⁸ USCCB, "A Century of Social Change: A Common Heritage, a Continuing Challenge," (Washington, DC: United States Conference of Catholic Bishops, 1990), pp. 1-2; "Sharing Catholic Social Teaching: Challenges and Directions," (Washington, DC: USCCB, 1998), Introduction; Pontifical Council for Justice and Peace, "Compendium of Social Doctrine," par. 3-5, 7.

¹⁹ Council Fathers of Vatican II, "Pastoral Constitution, Flannery," par 26; USCCB, "Economic Justice for All: Catholic Social Teaching and the U.S. Economy," (Washington, DC: United States Conference of Catholic Bishops, 1986; reprint, 1997), par. 77,79-80; "A Century of Social Change: A Common Heritage, a Continuing Challenge."

admits that its broad awareness and acceptance continues to elude many in the Church, both clergy and lay people.²⁰

Catholic faith says that every human being is a person, and is created in the image of God, which is the basis of every person's identity.²¹ This is the source of Catholic Social Teaching foundation of respect for the dignity of every human being. Someone's identity influences how others see them, talk about them, and treat them. Yet, as will be made clear in the unfolding pages, narratives about individuals with IDD are often inconsistent with their basic identity as a human person. Looking to scripture, we find an interesting example of disjointedness between self-understanding and narratives by others when Jesus asked his disciples how they and others perceived and talked about him. The resulting discourse provides the opening question and launch point, for my thesis, where we will now turn.

D. Who Do You Say That I Am?

Jesus wondered who people thought he was. There were different opinions, his disciples told him, "'John the Baptist, Elijah, or one of the prophets.' [Then] he asked, 'But who do you say that I am?' Peter answered him, 'You are the Messiah.' And he sternly ordered them not to tell anyone about him (Mark 8:28-30).'" Eugene LaVerdiere says that Jesus silenced them because he did not believe they understood what that meant. For them the Messiah would have earthly power, not be rejected, suffer and be

²⁰ "A Century of Social Change: A Common Heritage, a Continuing Challenge," p. 2; Pontifical Council for Justice and Peace, "Compendium of Social Doctrine," pp. xvii-xix, par 7, Letter from Cardinal Renato Raffaele Martino, President of the Pontifical Council for Justice and Peace, on purpose of the Compendium and Pope John Paul II's desire for its publication; USCCB, "Sharing Catholic Social Teaching," Introduction.

²¹ Catholic Church, CCC, par 27-34.

killed, as evidenced in Peter's rebuke of Jesus (Mk 8: 31-33).²² The disciples were seeing Jesus as they wished him to be, and created an identity that corresponds to that. How often do we do this ourselves, even with the significant people in our lives who we know very well?

Just as Jesus' asked the disciples who they thought he was, I raise this question to the US Catholic Church from individuals with IDD. Who someone is said to be is an accumulation and juxtaposition of the many stories about them, a tapestry woven from the various threads of different storytellers' voices. Each person shares their own story, but other people also contribute, both from direct experiences and from second-hand accounts. Therefore, no one really controls their story.²³ It is influenced by the multiple stories which coalesce into a metanarrative, which impacts how people are treated, how they understand themselves and what opportunities they may have for relationships and participation within community groups and events. Individual and community identity are informed by these stories.²⁴

1. *Stories and Narratives*

First I should differentiate narrative and story as I use them, because I realize some people use them interchangeably.²⁵ There are different kinds of stories, but

²² Eugene LaVerdiere, S.S.S., *The Beginning of the Gospel: Introducing the Gospel According to Mark*, vol. 2 (Collegeville, MN: Liturgical Press, 1999), pp. 15-35; "The Beginning of the Gospel of Jesus Christ with Eugene Laverdiere, Class Discussion." (paper presented at the College of Saint Elizabeth Summer Institute, College of Saint Elizabeth Convent Station, NJ, Summer 2003).

²³ John Swinton, Harriet Mowat, and Susannah Baines, "Whose Story Am I? Redescribing Profound Intellectual Disability in the Kingdom of God," *Journal of Religion, Disability & Health* 15, no. 1 (2011): pp. 11-12.

²⁴ H. Anderson and E. Foley, *Mighty Stories, Dangerous Rituals*, (San Francisco: Jossey-Bass, 2007). ch. 4, L 936.

²⁵ Jenny Rankin, "What Is Narrative?," *Concrescence: The Australasian Journal of Process Thought* 3 (2002): p. 2; Anderson and Foley, *Mighty Stories, Dangerous Rituals*. ch. 1, L 157.

relative to this project is their use in meaning making, helping an individual and/or community to understand events, themselves, or an interaction of the three. It begins with the particular and works toward some larger sense, which does not mean there is only one outcome. A story consists of characters and events and it typically has a beginning, middle and an end. Which events are included or highlighted can make a difference to the outcome of the story, in other words, the meaning learned. A narrative, however, presents a particular perspective to promote a set of values or vision, it intends to influence others.²⁶ Essentially, narrative provides a semantic coherence, rather than a sequential flow of events provided by story.

However, there is more than one way to tell a particular story, and each telling can lead to different insights. A person can decide to search for a different understanding or outcome by reassessing what is included in the unfolding story. In *Disability, Providence and Ethics* Hans Reinders illustrates this with the example of Amy Julia Becker working through the implications of her daughter being born with Down Syndrome. Tired of only focusing on what her daughter Penny will never do and what that means for her life, Becker steps back a bit and just enjoys being with Penny, leaving herself open to new areas of focus. Two events unfold which ultimately lead her to giving up previous expectations and recognizing that Penny is a beautiful gift just as she is. What her life will be like is still to unfold. Penny still has Down Syndrome and will grow up in a world where many people may not value her because of that. However, Becker's perspective has changed because she now sees it full of possibilities, within the unique person that Penny is. Rather than seeing Penny as her daughter with Down Syndrome, she comes to realize that she is "just Penny."²⁷

²⁶ Mieke Bal, *Narratology: Introduction to the Theory of Narrative*, (University of Toronto Press, 2009). ch. 2, L561; Anderson and Foley, *Mighty Stories, Dangerous Rituals*. ch. 1, L 170.

²⁷ Amy Julia Becker, *A Good and Perfect Gift: Faith, Expectations, and a Little Girl Named Penny*, Kindle ed. (Bethany House, 2011), pp. 88-166; Hans S. Reinders, *Disability, Providence, and Ethics: Bridging Gaps, Transforming Lives* (Baylor University Press, 2014), ch. 8, L 3458-3529.

In the example above, Becker was developing a story about her daughter, herself and their family. The process allowed her to work through questions and emotions that were troubling her that led to finding a new story. Once found and accepted, it became a narrative that would inform their lives. Becker recounts the impact of guidance from a developmental specialist she received when Penny was just two months old,

most parents of kids with disabilities focused on their child's weaknesses. Instead we should try to identify Penny's strengths and help her grow into those strengths. ... we would recognize how capable she really was. Ideally, the process would begin a happy feedback loop, where progress was made not because of fighting to get to the next goal, but because of getting to know our daughter as an individual who could do things in her way, in her time. ... [H]is words helped me realize that Penny wasn't a problem to be fixed. She was our daughter, a person to be loved.²⁸

The words of this specialist affirmed Becker's new narrative. Rather than focusing on deficits and problems, the work of her and her husband as Penny's parents were to support her development and launch her into the world as best as possible for her. This lesson will come up again during the constructive part of my thesis. For now, it is enough to illustrate the difference between story and narrative, as I use them.

So narrative functions as a coherent semantic web that provides a meaning-making map to apply to a particular subject, whereas a story relays unfolding events chronologically. A narrative begins with a particular message in mind, and a story does not. These parameters will provide background for the *shadow narrative* I will be exploring. The narrator constructs it by layering their own text over embedded texts about people and/or events. In this case, it references individuals with IDD and sometimes the general members of the Church. Within the narratives, individuals with IDD are either being characterized or positioned as objects of other people's concern or actions. Interestingly, the embedded texts are subordinate to the narrator's texts, although Mieke Bai says this is not intended as a value judgement, in *Narratology*:

²⁸ Becker, *A Good and Perfect Gift: Faith, Expectations, and a Little Girl Named Penny*, p. 158.

Introduction to the Theory of Narrative.²⁹ This is interesting, because as I will demonstrate, the *shadow narratives* about individuals with IDD presented in this chapter are told *about* them not *by* them and have played a significant role in marginalizing individuals with IDD in the Church and society at large, though it is less so.

The stories perceived, known and shared about people matter. They become the basis for the narratives about others. Challenging false narratives about oneself can be very difficult, even for very articulate individuals. Patronizing and sentimental stereotypes are at the heart of many stories about individuals with intellectual and developmental disabilities (IDD), despite the demonstrated growth in their abilities within mainstream society when they have access. It is particularly challenging for persons with I/DD who are often unable to tell their own stories and typically have less relationships within the community, which to a great extent is caused by sentimental and patronizing narratives about them. They are often considered to be the object of ministry, rather than its subject or partner within this framework, as opportunities for people to grow in grace through good actions on their behalf. This objectification and stereotyping undermines the possibility for meaningful participation, vocation development and sense of belonging within the Church, which puts its pastoral practice at odds with its theological and creedal statements.³⁰

Further clarity on what disability is in our discussion will be helpful, which is what I will address next.

²⁹ Bal, *Narratology: Introduction to the Theory of Narrative*. ch. 4, Relations between Primary and Embedded Texts, L1313.

³⁰ Catholic Church, CCC, 1271, 2030.

E. Note on Definitions, Models and Language

Models provide a framework to interpret the dynamics or beliefs about a particular issue and develop out of particular narratives which inform them.³¹

Concerning disabilities, the different models provide a particular lens on the human experience of disability from a particular point of view, that is reflected in its name. The existence of a model does not make its positions true; it simply explains them.³² For example, the medical model presents disability as something to be diagnosed and cured. Focusing on deficits, disability, according to this model is a tragedy. It can only be dealt with through treatment from the medical community to regain wholeness, or through services from charitable organizations and individuals to relieve suffering. The social model of disability sees disability as socially constructed by disabling elements in the environment, physical, social and attitudinal. The charity model of disability focuses on disability as an opportunity for charity, bemoaning its patronizing assumptions that perpetuate dependence, rather than foster flourishing. A model's particular lens then provide a conceptual structure that shapes responses, legislation, supports, services

³¹ Ian G Barbour, *Myths, Models, and Paradigms: A Comparative Study in Science and Religion*, (San Francisco, New York, London: Harper & Row 1976). Online Database. chap. 1, <http://www.religion-online.org/book-chapter/chapter-1-introduction-3/>.

³² Ibid., chap. 2, <http://www.religion-online.org/book-chapter/chapter-2-symbol-and-myth/>.

and attitudes for and about individuals with disabilities. These are very brief descriptions of models that are explored more deeply in many resources noted below.³³

I know about the different models because it is important to understand people's perspective on disability, however, my own position is one of theological anthropology. In other words, it is simply part of being human, one of the many categories of the incredibly diverse human family who are all created in the image of God.

It is important to realize the full variability amongst individuals with disabilities. Even the word disability has many different categories and interpretations. It can refer to intellectual, developmental, sensory, mobility, physical, learning, or emotional disabilities. The experience of disability is also profoundly impacted by when the disability occurs, if someone is born with it or acquires it during life. And if it is acquired during life, is it from an accident or does it evolve?

My thesis concerns the experience of individuals with (IDD) within the US Catholic Church. Although many of the issues and concerns apply to individuals with other disabilities, the rupture between theology and practice is sharpest for them. Even this specification is very broad, however. Developmental disability is the overarching category that includes a number of different disabilities that are severe and chronic, as well as intellectual and/or physical. It is evident before the person is 22 years old. Intellectual disability is assessed based on three areas: intellectual functioning, adaptive

³³ David Johnstone, *An Introduction to Disability Studies*, Second Edition, (2005; Great Britain: Routledge, 2001). pp. 22-27, 106-106; World Health Organization, "Towards a Common Language for Functioning, Disability and Health: ICF. Geneva, Switzerland: World Health Organization," (Retrieved 06/20/2012 from <http://www.who.int/classifications/icf/beginners/bg.pdf>, 2002); World Health Organization and The World Bank, "World Report on Disability," (Geneva, Switzerland: WHO, 2011); Dan Goodley, *Disability Studies: An Interdisciplinary Introduction*, (Los Angeles: Sage, 2017). pp. 1-26; Tom Shakespeare, *Disability Rights and Wrongs Revisited*, (New York: Routledge, 2014). pp. 1-69. The first three resources provide good introductions to the different models of disability. The last two resources provide a more nuanced exploration of the different issues associated with naming any one lens about disability.

behavior and must be evident before the person is 18 years old.³⁴ Just as with models, diagnostic labels have limited value within the body of Christ. They are only useful to the extent that they provide helpful information about a person, such as an idea of what types of supports may be helpful. However, different people with the same diagnosis will all be very different. They will have different interests, gifts, support needs, personalities, etc. The WHO resources cited above can provide more information, as well as AAIDD, cited within this paragraph.

A note on language – this discussion spans 70 years and language about persons with disabilities has continued to evolve and change. When quoting a document, I will use the language within the quoted document. When quoting the *Pastoral Statement of the U.S. Catholic Bishops on Persons with Disabilities*, I will typically use the language of the 1989 edition, renamed *Pastoral Statement of the U.S. Catholic Bishops on People with Disabilities*, which is the most consistent with current practice. There was no change in meaning nor any new ideas introduced in the different versions, only an attempt to recognize the impact of language and respect individuals with disabilities. I will use person first language in my discussions, but this also requires some clarification. Person-first language notes that individuals with disabilities are persons first, and has been generally preferred for quite a while. An example is to say, “a woman with Down Syndrome” or “who has Down Syndrome.” When someone says, “the Downs kid,” Down Syndrome becomes an adjective, defining the person and when alone, is the only definition of the person. It is like referring to me as “the arthritic woman.” For the same reason, “persons” or “individuals” with disabilities is preferred to “people with disabilities.” The first notes variety amongst individuals with disabilities, while the second implies a single set of characteristics. Even grouping people with the same disability doesn’t work. All individuals with autism or Down Syndrome are no more alike than all women, all men or all Americans. Disabilities cut across all groups of people.

³⁴ AAIDD, "Frequently Asked Questions on Intellectual Disability," American Association on Intellectual and Developmental Disabilities, <http://aaidd.org/intellectual-disability/definition/faqs-on-intellectual-disability>.

At the same time, some individuals with disabilities prefer what is known as identity language, to say, a “disabled person” or be referred to as “an autistic.” They recognize the culturally mediated narratives about individuals with disabilities and want to call attention to the disabling attitudes and structures, both in society and buildings, which are typically more disabling than their disability. Their disability is also a part of their identity, a part of how they experience the world, so they also reject the definition of what is considered “normal” by a dominant (and dominating) voice in society.³⁵

Words have potent implications on perceptions, attitudes and consequent actions. This reality is reflected in the changing landscape of language in ministry with persons with disabilities. NAMR changed its name to the National Apostolate with Mentally Retarded Persons (NAMRP) in 1978. Each word change was intentionally thought out. ‘For’ was changed to ‘With’ to acknowledge cooperative relationship, rather than a power-based one. This shift was happening in other areas of pastoral practice as well. ‘The Mentally Retarded’ was considered an empirical impersonal category, so gave way to ‘Mentally Retarded Person’ to reference full personhood.³⁶ The name changed again in 1992, by inserting ‘People’ before mental retardation, to emphasize the individual rather than the disability first, commonly referred to as person-first language. Interestingly enough, ‘People’ was considered to provide more importance than ‘Persons.’

The final name change was in 1997 to its final designation, the National Apostolate For Inclusive Ministry (NAFIM). The meaning of Apostolate evolved for the organization from referring to Jesus and his apostles, to invoking a lay ministry that includes all in the Church. “Specifically, we share the journey of persons with mental

³⁵ Goodley, *Disability Studies: An Interdisciplinary Introduction*. pp. 12-13; Shakespeare, *Disability Rights and Wrongs Revisited*. pp. 92-97.

³⁶ Fr. Robert Roger Lebel, S.J., "Guest Editorial: A Proposal," *NAMR Quarterly Publication* 9, no. 1 (1978): p. 2.

retardation in the life of our Catholic Church.”³⁷ It is interesting to note the use of ‘persons’ in its purpose, rather than ‘people.’ The value of using ‘persons’ over ‘people’ is that it acknowledges the individuality of every person with a disability, rather than applying a blanket set of characteristics. NAFIM’s statement of purpose changed in 2005 from “Supporting the Inclusion of Persons with Mental Retardation in the Catholic Church” to Promoting the Full Participation of Persons with Intellectual Disabilities in the Life of the Church.”³⁸

Other notes on language. “Church” will be capitalized when referring to the Roman Catholic Church, even if only as the Church. Collective references, such as churches is lowercase. I will use gender inclusive language whenever possible, and note editing from ecclesial documents in footnotes. The sixteen documents of Vatican Council Two are available in a translation with inclusive language, however, other conciliar texts and speeches are not, along with some papal documents that are cited.

F. Methodology

To answer my research question and explain the rupture between professional statements of the US Catholic Church and its pastoral practices regarding individuals with disabilities and why it persists, I explored in the critical part the history of ministry with persons with IDD in the US Catholic Church in conjunction with its primary ecclesial document on the subject, the *Pastoral Statement of the U.S. Catholic Bishops on Persons with Disabilities*. While doing so, I discovered a narrative woven throughout this history that I named the *shadow narrative*, because it contradicts the basic premises of Catholic Social Teaching and eclipses the light of the Gospel. Tracing the *shadow narrative*, I discerned that its most pervasive, persistent and therefore most troublesome thread concerns the misconstrued version charity, necessitating further backward

³⁷ Barbara J. Lampe, "The Story of the National Apostolate for Inclusion Ministry," *Journal of Religion, Disability & Health* 10, no. 1-2 (2006): p. 59.

³⁸ Ibid., p. 60.

glances in time. My constructive offering starts with the theological account of the body of Christ as the framework in which I want to think about a positive response to the *shadow narrative*. To think about the practical implications of this framework, I turn to *Social Role Valorization Theory* (SRV). It provides the explanation as to why the *shadow narrative* persists within the Church and a method to counter long held practices and mindsets. The body of Christ positively engages the principles of Catholic Social Teaching and SRV, holding together the tensions between individual and community concerns, to address a persistent problem, to re-educate the Church at large and reform it within its self-proclaimed identity.

My primary sources for exploring the history of ministry with persons with IDD are US ecclesial documents, pastoral and peer-reviewed journals, archives, interviews, and situations from my own experiences as the Director for Pastoral Ministry with Persons with Disabilities in the Archdiocese of Newark, where I have worked since 2005. The stories shared throughout the thesis are used to illustrate particular points and possibilities. The *US Pastoral Statement* is the foundational theological statement within the US Catholic Church at the intersection of theology, disability and pastoral practice and therefore guides my line of inquiry, though I also access other documents that either influenced its development or draw from it to speak to specific situations, such as catechesis and sacrament participation.

I discovered the necessary evidence to answer my opening question in the developing and early years of the ministry, with some notable additions around promulgations of the *Guidelines for Celebration of the Sacraments with Persons with Disabilities* (1995) and *National Catechetical Directory* (2005). Therefore, I emphasized those examples in chapters two and three, though not exclusively. Devoting more time to the intervening years would have revealed many interesting moments in the ministry and more pioneers certainly worth remembering, but would not have influenced the outcome of my thesis other than to make it much longer. Later illustrative examples that echo the earlier ones are woven throughout the remainder of the text.

Catholic Social Teaching guides my analysis of the theological integrity of pastoral practices within the US Catholic Church and frames my proposal for a

corrective response. It must be noted that while the principles of Catholic Social Teaching can be considered static, how they are understood and articulated continues to evolve as it responds to the changing dynamics of human society, as already indicated. These shifts are made in papal and bishop conferences' texts. I rely on the documents of Vatican II in general in chapter two, to provide the cohesive foundation for further development of Catholic Social Teaching, particularly the Document on Religious Liberty (*Dignitatis Humanae*) and the Pastoral Constitution on the Church in the Modern World (*Gaudium et Spes*), because they significantly influenced the US Pastoral Statement.

I also draw on some later ecclesial documents of Catholic Social Teaching by the US Catholic Bishops and the Compendium of the Social Doctrine of the Church by the Pontifical Council for Justice and Peace, as well as some specific papal documents. While I discuss some instances of the shadow narrative in some of these other ecclesial sources and their implications, my detailed analysis is restricted to the US Pastoral Statement for two main reasons. First, it provides the vision for the US Catholic Church, so what it says and how it is understood heavily impacts the lived experiences of people at the intersections of theology, disability and pastoral practice and is the valid standard to assess practice. Second, this decision provides boundaries for the discussion that allows me to also provide a constructive response to the problem.

Given my discovery of the shadow narrative, I needed to distinguish between narratives and stories. Explaining Tradition within the Catholic Church is necessary to clarify its living nature. This is critical to understand the significance of the Council Fathers' determination on human dignity at the Second Vatican Council and the challenges it presents for interpretation and understanding amongst all in the Church, clergy, religious and lay people.

My exploration of charity tradition is not an exhaustive historical analysis, but more a probing into formational shifts that seem to foreshadow current dilemmas noted in its current form. Here I rely on the work of scholars in Jewish, Christian and monastic charity histories for guidance. Scripture, hermeneutical texts and peer-reviewed journals and books are my primary sources when considering the body of Christ as a theological

framework for the constructive portion of my thesis. For SRV I utilized many of Wolfensberger's own text, but also those of others, and interviews with some of his contemporaries. I have also drawn from other specific disciplines within the social sciences that complement or support aspects of SRV, particularly the psychologist Jamil Zaki's work on the motivational theory of empathy and his summary review of others' work.

To explain my primary use of Catholic sources bears mentioning. When I first began working in this ministry, I was just completing my master's in theology. I was very interested in virtue ethics, intrigued by implications of Karl Rahner's eschatology for everyday life and John Courtney Murray's work on religious liberty, human dignity and interfaith collaboration for the common good. These sources, in addition to the US Pastoral Statement and other documents on Catholic Social Teaching sufficiently frames the work of this ministry. However, I want to be clear that my utilization of these sources has been greatly enhanced by my own engagement with the many voices noted earlier from other traditions.

One more explanation will be helpful before moving into the substance of my research. Throughout my discussion I refer to the 'intersection of theology, disability and pastoral practice' or 'theology and disability' and intentionally avoid saying 'disability theology.' Disability is recognized to be part of the human condition within international statements.³⁹ Yet, individuals with disabilities continue to be considered different than 'ordinary' people. I believe the experience of disability needs to be woven throughout all theological and ecclesial texts to reinforce it is a natural part of being human and also to acknowledge its diversity, which is an essential characteristic of humanity as well. I hope my intentional language will further this goal. Having laid out my inquiry, its purpose, import, context and framework, I will share the results of my quest in the next chapter, why individuals with IDD are marginalized in the US Catholic Church.

³⁹ World Health Organization, "Towards a Common Language for Functioning, Disability and Health: ICF. Geneva, Switzerland: World Health Organization."; Ad Hoc Committee of the General Assembly, "Convention on the Rights of Persons with Disabilities," (New York: United Nations, 2006).

II. The US Catholic Church at the Intersection of Theology, Disability and Pastoral Practice

Faith is important to 87% of individuals with disabilities and to 84% of individuals without disabilities, yet they do not participate in similar numbers.⁴⁰ Only 45% of individuals with severe disabilities participate in faith communities compared to 57% of individuals without.⁴¹ The purpose of this chapter is to present the very clearly articulated theological framework on disability of the US Catholic Church juxtaposed with its impact on the lived reality of individuals with disability at the local level, and suggest possible reasons for this ongoing elusiveness. This vision is proclaimed in the *Pastoral Statement of the U.S. Catholic Bishops on Persons with Disabilities (Pastoral Statement)*, which was promulgated in 1978. It is heavily steeped in the theology of the Vatican II, which provides much of the framework for what has become known as Catholic Social Teaching, discussed in the last chapter. Therefore, a brief discussion of the Second Vatican Council will provide important context for the *Pastoral Statement*. I will provide a general overview of the history of ministry with persons with IDD in the US Catholic Church, both leading up to the *Pastoral Statement* and afterward, which will provide the framework to suggest possible reasons for the discrepancy between theological pronouncements and pastoral practices and experiences of individuals with disabilities.

My discussion on the history of ministry with persons with disabilities will focus on providing a general sense of its development and its early years leading up to the *Pastoral Statement*, both as it informed and was informed by a theology on disability pronounced by the US Bishops. In this I will focus on general trends, beliefs and practices illustrated by particular moments which tell the story of disability in the US Catholic Church which seem to give insight into the problems which persist today. I

⁴⁰ Harris Interactive, "2004 National Organization on Disability/Harris Survey of Americans with Disabilities," in *The National Organization on Disability* (2004).

⁴¹ "The ADA, 20 Years Later," in *Survey of Americans with disabilities* (New York: National Organization on Disability and Kessler Foundation, 2010).

have decided to include very little discussion about the intervening years between the promulgation of the *Pastoral Statement* and today for two reasons. First, I discovered that the stated purpose of ministry with persons with disabilities was very much the same as it is today, and second, similar patterns of contradicting pastoral practice and guidance have been present throughout the development of the ministry, and I found them in the *Pastoral Statement*, pastoral practices and journal articles on the ministry. Instead of flooding the reader with details over 70 years, I selected key moments that illustrate the important themes and will use these to facilitate the discussion of my findings.

Within the contradictions, I perceived a counter narrative to the one being proclaimed in essential statements of faith about human dignity and all the rights and responsibilities this entails. I have named this narrative the *shadow narrative*, because like a shadow, it is hidden, and it hides things. For the purposes of this discussion, it hides or dims the light of the Gospel. Forty years after the *Pastoral Statement* was promulgated, the Church still struggles to appreciate the gifts, uniqueness and experiences of individuals with IDD it calls for.⁴² “Why is this? Why are individuals with IDD marginalized within the Church, despite the fact that this practice contradicts everything it professes about itself?” This chapter is the first step to answering this question and lays out the story and answers unearthed.

A. *Vatican II: The Dawning of a World Church and Framework for Catholic Social Teaching*

Pope John the XXIII initiated a seismic shift in the Church’s relationship with the world when he called for the Second Vatican Council on January 25, 1959 to initiate a renewal of the Church so that it could live out the gospel more faithfully and engage with

⁴² USCCB, “Revised Guidelines,” Preamble.

the world on the problems of the day that undermined human dignity and flourishing.⁴³ In his opening speech he noted that human society was being led by Divine Providence to a new order of relations, through people's efforts that would fulfill God's will beyond their expectations. "And everything, even human differences, leads to the greater good of the Church."⁴⁴ Rather than continuing to export a static "European religion as a commodity" Karl Rahner said, the Council was a first step toward truly becoming a world church, one that would reciprocally engage its different parts.⁴⁵ Where previously the Church provided its own ready answers for the problems of the day, it now promised to engage with the world to learn and more effectively serve humanity based on the needs of the day. Rahner believed this would lead to a recognition for culturally based interpretations of the one faith, to honor the multidimensional nature of humanity and diverse cultural and historical contexts.⁴⁶ At the Council, Catholic and non-Catholic men and women were invited to observe, and in some cases, to provide responses to the finished documents. Albert Coulter, a Methodist invited as an observer at the Council, noted in his responding commentary on *Lumen Gentium*, the *Dogmatic Constitution on the Church* that the Church projected a new vision of itself in conversation with the

⁴³ Lawrence Cardinal Shehan, "Introduction," ed. Walter M Abbott, Kindle Edition ed., *The Documents of Vatican II: Introductions and Commentaries by Catholic Bishops and Experts, Responses by Protestant and Orthodox Scholars* (America Press Inc., 1966; repr., April 30, 2012).

⁴⁴ Pope John XXIII, "Pope John's Opening Speech to the Council," *ibid.* (New York). L17421-17541.

⁴⁵ Karl Rahner, "Towards a Fundamental Theological Interpretation of Vatican II," *Theological studies* 40, no. 4 (1979): pp. 716-727.

⁴⁶ Krauss Meinold, *Karl Rahner: I Remember, an Autobiographical Interview with Meinold Krauss*, ed. Harvey D. Egan, S.J. (Crossroad, 1985), pp. 91-92.

world during Vatican II and demonstrated the ability for self-criticism and a sincere interest in ecumenical dialogue.⁴⁷

1. *Human Dignity*

The shift that Rahner referred to centered on the defining role that respecting the dignity of every person instigated. Vatican II is regularly referred to as a pastoral council concerned with bringing the Church into a renewed relationship with the world to support human flourishing and to re-present Catholic teaching in culturally mediated ways to increase understanding and relevancy. However, the Council Fathers did declare important new doctrinal points when they named human dignity as the foundational principle for moral action and approved the development of doctrine to maintain integrity of faith. This was hotly contested during the development and eventual passing of *Dignitatis Humanae*, the *Declaration on Religious Freedom (Religious Freedom)*.⁴⁸ Whereas previously primordial right was given to Church authority as the one true faith, *Religious Freedom* stipulated that human dignity, not truth, is the foundation for religious freedom, which is endowed with free will and reason, and so cannot be developed by external coercion. Therefore, subjective ability or choice does not negate the right. The case was won through demonstrating the break in papal teaching regarding religious freedom beginning with Pope Pius XII, that continued with subsequent popes, most recently at the time by Pope John XXIII,

⁴⁷ Albert Coulter, "Dogmatic Constitution on the Church: A Response," in *The Documents of Vatican II: Introductions and Commentaries by Catholic Bishops and Experts, Responses by Protestant and Orthodox Scholars*, ed. Walter M Abbott (New York: America Press Inc., 1966; reprint, April 30, 2012), p. 103.

⁴⁸ The Latin name of papal and Vatican documents refer to the opening words of the document, and therefore provide insight to its central theme. For this reason, I will list the Latin name when first mentioning the document, as well as its English title, which does not provide the same insights.

speaking to the world about the inalienable rights of all human beings as persons.⁴⁹ The encyclical was written in 1963, commenting on the changing dynamics of the social order in the world that was developing in large part because of the general increasing awareness by people of their innate dignity, leading them to demand recognition and acceptance of their rights.⁵⁰

Human dignity became the linchpin for religious freedom, but also to hold the principles of Catholic social doctrine together. Recall that human dignity dictates expectations of what is due to a person. This was woven throughout the conciliar texts, particularly in the *Gaudium et Spes*, *Dignitatis Humanae*, and *Lumen Gentium*.⁵¹ Acceptance of freedom from coercion based on human dignity was required for *Unitatis Redintegratio* and *Nostra Aetate*, but it would also be required if the Church wished to

⁴⁹ Council Fathers of Vatican II, "Declaration on Religious Liberty (*Dignitatis Humanae*)," ed. Austin Flannery, Kindle ed., *Vatican Council II: Constitutions, Decrees, Declarations: The Basic Sixteen Documents. A Completely Revised Translation in Inclusive Language* (Collegeville, MN: Liturgical Press, 1996; repr., 2014). par 1-2; John Courtney Murray, "Religious Freedom," ed. Walter M Abbott, Kindle Edition ed., *The Documents of Vatican II: Introductions and Commentaries by Catholic Bishops and Experts, Responses by Protestant and Orthodox Scholars* (New York: America Press Inc., 1966; repr., April 30, 2012). Introduction to the document, L 16498-16539. For more in depth discussion on both of these issues: Charles Morris, *American Catholic: The Saints and Sinners Who Built America's Most Powerful Church*, (New York: Vintage, 2011). p. 69; Murray, *The Problem of Religious Freedom*, pp. 58-64. Morris, notes that freedom of conscience was disclaimed by Gregory XVI in 1832, and Pius IX in 1864. Murray's discussion centers on the development of doctrine as discussed in Ch. 1.

⁵⁰ Pope John XXIII, "Pacem in Terris (Peace on Earth)," (Vatican City: Libreria Editrice Vaticana, 1963), par 41, 71.

⁵¹ Council Fathers of Vatican II, *The Documents of Vatican II: Introductions and Commentaries by Catholic Bishops and Experts, Responses by Protestant and Orthodox Scholars*, (April 30, 2012; New York: America Press Inc., 1966). English titles: *Pastoral Constitution on the Church in the Modern World*, *Declaration on Religious Liberty*, and *Dogmatic Constitution on the Church in the Modern World*, respectively. Searching the Kindle edition, I counted dignity referenced 153 times, 11 in *Dogmatic Constitution*, 59 in *Pastoral Constitution*, and 23 in *Religious Freedom*. The remaining 40 were woven throughout the remaining text.

speak with any moral authority on world issues.⁵² Beyond freedom from coercion, it also implies the freedom *for* many things, which the *Pastoral Constitution* goes into at great length. Human flourishing was an issue important at the Council, as well as freedom and peace. The horrors of two world wars and the implications of globalization and technical innovations influenced the conversations as well.⁵³

The *Pastoral Constitution of the Church in the Modern World (Pastoral Constitution)* was not part of the Council's original preparatory documents, but grew out of the Council Fathers' collective discussions during the opening session. They wished to present a central vision of the Church to the world regarding its self-understanding that would explain its presence and activity in the world.⁵⁴ Its Latin name, *Gaudium et spes*, comes from the first three words of its first sentence, which says much about the document's message, "*The joy and hopes, the grief and anguish of the people of our time, especially those who are poor or afflicted, are the joys and hopes, the grief and anguish of the followers of Christ as well.*"⁵⁵ The document builds on the foundational premise of human dignity of all people who are created in the image of God.⁵⁶

⁵² Xavier Rynne, *Vatican Council II*, 3rd ed. (Maryknoll, NY: Orbis Books, 1996; repr., 1999), p. 466. The Decree on Ecumenism and the Declaration on the Relationship of the Church to Non-Christian Religions, respectively, would mean little without acceptance of both points. Also, Pope Paul VI's was scheduled to address the United Nations Assembly to support respect for human dignity and peace on October 4th.

⁵³ Council Fathers of Vatican II, "Pastoral Constitution, Flannery."par 77-92

⁵⁴ Donald R. Campion, S.J., "The Church Today," ed. Walter M. Abbott, Kindle ed., *The Documents of Vatican II: In a New and Definitive Translation, with Commentaries and Notes by Catholic, Protestant, and Orthodox Authorities* (New York: Crossroad Publishing Company, 1966; repr., April 30, 2012). Introduction to the Pastoral, L4840.

⁵⁵ Council Fathers of Vatican II, "Pastoral Constitution, Flannery," par 1.

⁵⁶ "Pastoral Constitution on the Church in the Modern World (*Gaudium Et Spes*)," ed. Walter M. Abbott, Kindle Edition ed., *The Documents of Vatican II: Introductions and Commentaries by Catholic Bishops and Experts, Responses by Protestant and Orthodox Scholars* (New York: America Press Inc., 1966; repr., April 30, 2012). par 11-22.

Therefore, the Church, collectively and in its individual members, cannot ignore the needs of people required for human development and flourishing.⁵⁷ The framework and essential content of Catholic Social Teaching presented in the first chapter comes from the *Pastoral Constitution*. Recognizing the social nature of humanity, it emphasizes the importance of relationships in life and for the development of one's gifts, but also for social progress as well. Concern and scope of the common good is continually expanding as humanity becomes increasingly interdependent.⁵⁸ Because of this growing interconnectedness, true Christians must feel the joy and pain of others as one's own in a most dramatic way and

... look upon his or her neighbor (without any exception) as another self, bearing in mind especially their neighbor's life and the means needed for a dignified way of life. ... Any offences against human life ... integrity ... and dignity are criminal: they poison civilization; and they debase the perpetrators more than the victims and militate against the honor of the creator.⁵⁹

Concern for the common good, human dignity, freedom and justice figure prominently in the call for the right of persons, "to live a genuinely human life."⁶⁰ The Council Fathers addressed all people about its central mission to be Christ in the world.⁶¹

Because everything else flows from the premise of human dignity as the starting point of all thought and action, according to Catholic Social Teaching, the purpose of society is for the benefit of persons, not the other way around. Therefore, differences in abilities and attributes are part of the diversity within the human family, and do not lessen or increase their likeness to the image of God, "everyone enjoy[s] the same

⁵⁷ "Pastoral Constitution, Flannery," par 23-32, especially 26.

⁵⁸ Ibid., par 12, 23-39.

⁵⁹ Ibid., par 27.

⁶⁰ Ibid., par 26.

⁶¹ Council Fathers of Vatican II, "Message to Humanity," ed. Walter M Abbott, Kindle Edition ed., *The Documents of Vatican II: Introductions and Commentaries by Catholic Bishops and Experts, Responses by Protestant and Orthodox Scholars* (New York: America Press Inc., 1966; repr., April 30, 2012). L406.

divine calling and destiny ... [T]heir equal dignity as persons demands that we strive for fairer and more humane conditions. Excessive economic and social disparity between individuals and peoples of the one human race is a source of scandal and militates against social justice, equity, human dignity, as well as social and international peace.”⁶² Lacking this makes it difficult for someone to exercise true freedom, because impoverished conditions can undermine one’s sense of dignity.

Building on this is the requirement for proper education to develop an informed conscience for responsible participation in community life, which is part of the Catholic Social Teaching principle of subsidiarity.⁶³ As Christians the principle of solidarity is rooted in the “communitarian character [that] is perfected and fulfilled in the work of Jesus Christ, for the Word made flesh willed to take his place in human society.”⁶⁴ These are the seeds from which the *US Pastoral Statement* grows. Just as the Council Fathers spoke pastorally of the role of the Church in the modern world to collaborate on the needs of humanity, the US Bishops would speak pastorally of its role and responsibility in the US, specifically relative to persons with disabilities, for the purpose of this discussion.

B. Beginning of a National Ministry – Preparing for the Pastoral

Ministry with persons with IDD was first organized nationally in the US Catholic Church through the National Apostolate for the Mentally Retarded⁶⁵ (NAMR) in 1968, after six years of planning, to be “wholly concerned with the total integration of the mentally retarded in the full life of the Church and the life of the community as “people of

⁶² "Pastoral Constitution, Flannery," par 29.

⁶³ Ibid., par 31.

⁶⁴ Ibid., par 32.

⁶⁵ The name was changed to the National Apostolate for Mentally Retarded Persons (NAMRP) in 1978, to National Apostolate for People with Mental Retardation in 1992 and finally the National Apostolate For Inclusive Ministry (NAFIM) in 1997. This is discussed more in the first chapter under language.

God.”⁶⁶ The organization received an Apostolic Benediction from Pope Paul the VI shared in a letter by the US Apostolic Delegate. It was addressed to, Fr. Matthew Pesaniello of the Archdiocese of Newark, its first president and all its members.⁶⁷ Richard Cardinal Cushing, Archbishop of Boston, was NAMR’s honorary President and Episcopal Advisor. In his own words, he was very happy about this association, as the work was very important to him. “From the moment I became Archbishop of Boston, I resolved to do everything in my power to provide for the care and training of these best loved children of God. According to Cushing, persons with IDD are “exceptional children,” because “‘they’ afford ‘us’ an exceptional opportunity of service.”⁶⁸

1. Movements Coming Together

This did not happen in isolation. A groundswell of movements had been brewing in the United States and around the world concerning human dignity, already noted in the Vatican II discussion, coalesced during the early 1960’s to influence attitudes about persons with IDD and called for pastoral responsiveness in the Church. Three movements in particular were coming together.

Parents were an important force in the early development of ministry with persons with IDD in the US Catholic Church, just as they had been in the development of education and services for their children born with IDD. These parents had resisted their doctors’ recommendations to send their sons and daughters to institutions, rather than living at home. As early as the 1940’s they organized local networks for education which evolved into larger networks to promote the general welfare of children of all ages with mental retardation through research and collaboration with public, private, state, federal, and religious organizations. They established the national organization, today

⁶⁶ Rev. Matthew M. Pesaniello, "Why a “National Apostolate for the Mentally Retarded”?," *NAMR Quarterly Publication* 1, no. 1 (1968): p. 3.

⁶⁷ Apostolic Delegate, "Apostolic Letter Notification of Benediction from Pope Paul VI on Work of NAMR," *NAMR* 1, no. 1 (1968): p. 1.

⁶⁸ Richard Cardinal Cushing, "Letter to Fr. Matthew Pesaniello," *NAMR Quarterly Publication* 1, no. 1 (1968): p. 2.

known as The Arc in 1950.⁶⁹ At its first conference in Minnesota, newspaper coverage quoted a parent, "We hope someday that our sons and daughters will not be tax burdens."⁷⁰ Norman "David" Atkins was born with cerebral palsy in 1944. His parents resisted doctors' recommendations to send David to an institution three times, when he was three, four and six-years old. David not only was not a tax burden, he was able to help support his mother and three siblings still at home when their father died at the age of 49. They could stay in the family home, thanks to David's income as a mail handler.

The United States government was calling on faith communities to step up their attention and support. The White House Conference on Children and Youth in 1960 listed individuals with IDD as the third highest significant area of concern and called on churches and synagogues to provide pastoral and therapeutic support for individuals and families living with disabilities, through educating seminarians, clergy and congregants, and to support community participation.⁷¹ Critically, this was the government commenting on the importance of spirituality and faith for all people, including individuals with IDD, even though it would take some time to be included in state and local support planning. Still, it put faith communities on notice about their responsibility almost 60 years ago.

President Kennedy appealed to Congress for a comprehensive response to intellectual disability, on February 5, 1963. "We as a nation have long neglected the mentally ill and the mentally retarded[sic]. This neglect must end if our nation is to live up to its own standards and dignity and achieve the maximum use of its manpower."

⁶⁹ Robert L. Schalock and Michael L. Wehmeyer, "The Parent Movement: Late Modern Times: 1950 CE to 1989 CE," in *The Story of Intellectual Disability: An Evolution of Meaning, Understanding, and Public Perception*, ed. Michael L. Wehmeyer (Baltimore, London and Sydney: Brookes Publishing, 2013), pp. 212-215. Original name was The National Association of Parents and Friends of Retarded Children.

⁷⁰ Minnesota Governor's Council on Developmental Disabilities, "The Fight for Civil Rights for People with Disabilities," Minnesota Governor's Council on Developmental Disabilities, disabilityjustice.org.

⁷¹ Rev. Matthew M. Pesaniello, "The Role of Administration by the Church in the Special Education Field," *NAMR Quarterly Publication* 1, no. DECEMBER (1968): p. 1.

Kennedy signed legislation moving toward community-based-systems.⁷² Because of their visibility, the experiences and example of the Kennedy family had a profound impact within the United States, if not the world.⁷³ Also, the children of the early parent movement were now young adults, and a number of them were seeking support for the opportunity to be independent.⁷⁴

The Vatican collaborated with The International Catholic Child Bureau⁷⁵ to plan an international conference on "Social, Professional and Religious Integration of the Mentally Retarded." The conference was organized by the Medico-Pedagogical and Psycho-Social Commission of BICE and took place in Rome, January 29-Feb 1, 1965.⁷⁶ Sixty-one experts gathered to discuss the social, professional and ecclesial integration

⁷² Ibid., p. 2. Pesaniello included highlights from President Kennedy's message to Congress on February 5, 1963. Though Kennedy was advancing responsibility of US to its citizens with ID, Pesaniello was claiming as relevant or more so to the Church.

⁷³ Schalock and Wehmeyer, "The Parent Movement: Late Modern Times: 1950 CE to 1989 CE," pp. 199-209.

⁷⁴ Minnesota Governor's Council on Developmental Disabilities, "The Fight for Civil Rights for People with Disabilities".

⁷⁵ Though its official name is as noted above, its acronym is BICE, for International Catholique de l'Enfance. It was founded in Paris as a tool to serve those who, in the Catholic world, are working to establish the rights of children and to ensure their comprehensive growth. It made a decisive contribution to the drafting of the 1989 United Nations Convention on the Rights of the Child.

<http://www.laityfamilylife.va/content/laityfamilylife/en/sezione-laici/repertorio/uff-cattolicoinfanzia.html>

⁷⁶ The conference was chaired by Dr. C. Busnelli, professor at the University of Perugia. Miss Marie-Hélène Mathieu and Father Henri Bissonnier, Secretaries General of the Commission, were also instrumental. This conference is, sadly, poorly documented. However, I am indebted to my friend, Talitha Cooreman at UCLouvain, and her colleague Lucia Ferretti Université du Québec à Trois-Rivières, who then called on Louise Bienvenue, who reached out to Kathy Rose, who contacted Sylvie Fournier, all at Université de Sherbrooke for assisting me and discovering helpful context of the conference, what countries participated and the discipline that organized it.

of individuals with IDD from 12 countries (Germany, Belgium, Brazil, Canada, Spain, France, Italy, Luxembourg, Netherlands, Portugal, Switzerland, USA), as well as the Vatican Secretary of State, Msgr. Luoni. The conference reinforced the innate dignity of the human person, regardless of ability or disability, challenging national Catholic education and apostolate organizations to honor “their responsibilities to integrate the handicapped into the life of the Church and not to reject even the most severely handicapped or their parents.”⁷⁷ Doing this requires respecting and promoting the ability of individuals with intellectual disability to learn and develop when provided with adequate education that challenges growth and opportunities for meaningful work with appropriate pay and social integration.⁷⁸ Both the vision and fact of the conference is significant. The vision is forward thinking and the conference took place in between the two final sessions of Vatican II, giving credence to its emphasis on human dignity. Between the focus of the conference and the countries that participated, it seems likely that the principle of normalization was an influence.

2. *Getting Started*

From the beginning the ministry with persons with IDD was a collaborative effort by clergy, religious,⁷⁹ parents, individuals with disabilities, and professionals. Activity had been percolating in different parishes around the United States at the grassroots level since the 1950's, and the mixture of talents and stakeholders continued in NAMR. The primary attention tended to be religious education and participation in the sacramental life of the Church, with some attention given to the concerns of families,

⁷⁷ Msgr. Francis R. LoBianco, PhD, "The Spiritual Equality of All God's Children," *NAMR Quarterly Publication* 1, no. 1 (1968): p. 9.

⁷⁸ Ibid.

⁷⁹ In the Catholic Church “men and women religious” refer to men and women who have taken vows within particular religious orders, such as Jesuit for men, Sisters of Charity of Convent Station for women. They are not ordained, so are not clergy. They typically live in community, but not always.

primarily parents. The inaugural issue of the NAMR Journal shared some suggestions for sacramental guidelines and catechetical models.

NAMR early effort focused on seeking to raise awareness, provide guidance and foster development of the ministry. Its work was carried out mostly through its journal and national conferences that addressed issues relevant to developing and managing different aspects of ministry with persons with IDD, as well as engaging with the NCCB/USCC to advance its work.⁸⁰ Pesaniello argued that the need for the new organization was rooted in the primary purpose of Catholic education, which is as true for individuals with intellectual disability as for all people. Yet, he predicted that the bishops would only become attentive to the spiritual vacuum in which persons with I/DD lived on the fringe of Church, when prompted by society and governments, to recognize that the needs of persons with IDD are the same as those for all of God's people.⁸¹

Regarding catechesis, Fr. Richard Kieran of the Archdiocese of Atlanta shared general principles, which requires respect for the person's education needs to adjust expectations based on the degree of intellectual disability. If someone could understand more, then this should be nurtured, but expectations for someone who understood less should be adjusted accordingly and should be focused on the individual, rather than the

⁸⁰ NCCB refers to the National Catholic College of Bishops and it managed church affairs by the bishops. The USCC refers to US Catholic Conference, an organization in which the bishops collaborated with other Catholics regarding the concerns of the Church for the larger societies of the world. Committees included bishops, lay people, religious and clergy. NCCB was created in 1966 based on recommendations of Vatican II and the National Catholic War Council (NCWC) became the USCC. It was founded in 1917 in reaction to WWI to organize Catholic war efforts and liaise with the US government. They combined July 1, 2001. All work is now done by 17 committees of bishops. <http://www.usccb.org/about/usccb-timeline-1917-2017.cfm>

⁸¹ Pesaniello, "The Role of Administration by the Church in the Special Education Field," p. 2.

curriculum.⁸² Another model was shared in the first issue by NAMR Board, "Special Religious Education Centers for Mentally Retarded Children." Roles, leadership, environment, materials, transportation, training and accountability are all laid out. Teens were recommended for support roles. Parents were to be strongly encouraged to participate in the parent program. The required attitude for a successful program stated all people working with

the mentally retarded must have a genuine love and affection for the children. Sentiments such as pity often are detriments to successful work with the children and their parents. Persons involved in the program should recognize the mentally retarded for what they are: chosen souls of God, sinless and loving, needing training and encouragement, and above all – love – to help them reach the potential that they possess ... Our Lord ... will enrich their spirits through the charity of the work they do for His holy innocents.⁸³

This is such an interesting quote because of its built-in contradictions. It recognizes the ability of individuals with IDD to learn and develop and discourages pity, though only says it is often detrimental to successful work, implying pity may be an appropriate attitude. Then in the next sentence it says that they are "chosen souls of God, sinless and loving." This clearly states that individuals with ID are intentionally designated by God, and that they are categorically loving and without sin. Charity is implied positively within this framework and they will be rewarded for doing "for His holy innocents."

Another article, among others, in other editions makes a curious counterpoint to the above, when discussing the three challenging attitudes that pastoral leaders faced regularly: the perception that intellectual ability was required for a life in grace, low expectations regarding the potential for individuals with IDD to learn, or "Why bother,

⁸² Rev. Richard A. Kieran, "Guidelines for the Pastoral Care of the Mentally Retarded," *ibid.*, no. December: p. 5; Philip Roos and Brian M. McCann, "Major Trends in Mental Retardation," *International Journal of Mental Health* 6, no. 1 (1977): p. 3. Kieran used terms educable and trainable, which were the education terms of the day for someone with mild, moderate or severe ID. Someone with profound ID was not considered trainable.

⁸³ NAMR Board, "Organizing the Special Religious Education Center for Mentally Retarded Children," *NAMR Quarterly Publication* 1, no. 1 (1968): pp. 14-15, 20.

they can't sin anyway?"⁸⁴ Fr. Kieran explained the perception, "Once baptized, they were simplistically styled "saints," which meant nothing else was required sacramentally, "Their relationship with God was regarded as being permanent, but static."⁸⁵ I frequently discovered such contradictions." There seems to be no realization how they contradict each other. The particular influences of these sentiments will be discussed more in the next chapter on the *shadow narrative*.

Regarding sacraments, the overarching inclination in the *Atlanta Guidelines* encouraged inclusive participation within the life of the Church, although religious education was mostly separate and 'special' liturgies were noted. The minimum requirement for readiness to receive Eucharist was, and still is, the ability to distinguish the host as different from ordinary food and to demonstrate a desire to receive God. Kieran also said it was believed that the Church supplies the necessary understanding for those who do not understand this, which was apparently accepted practice at the time, though not universally.⁸⁶ Advanced for its day, the guidelines also discussed marriage and noted that there were many individuals with IDD who were married, though Kieran expected this was not known or understood by the bishops.⁸⁷

⁸⁴ NAMR Board, "Toward a National Catechetical Directory Part 1," *ibid.* 5, no. 2 (1974): p. 7.

⁸⁵ Kieran, "Guidelines for the Pastoral Care of the Mentally Retarded," p. 5.

⁸⁶ *Ibid.*, p. 6. The last sentiment in this quote from Kieran was repeated by other diocesan pastoral guidelines in the US and England, however, it was not included in the US Bishops Guidelines promulgated in 1995, and in a letter dated April 27, 1984 from Fr. John Alesandro, Chancellor of Diocese of Rockville Centre, NY, to Bishop Walter Sullivan, Diocese of Richmond, Alesandro advises this is not accurate per canon 913. ; Oddly enough, Kieran's understanding was later validated during Bishop Synod on the Eucharist. Pope Benedict XVI, "Sacramentum Caritatis," (Vatican: Libreria Editrice Vaticana, 2007), par. 58; Pontifical Council for the Promotion of the New Evangelization, "Directory for Catechesis," (Washington, D.C.: USCCB, 2020), par. 272. Based on the above Post-Synodal Exhortation, new directory from Vatican says, "no-one can refuse the sacraments to persons with disabilities."

⁸⁷ Kieran, "Guidelines for the Pastoral Care of the Mentally Retarded," p. 8.

Throughout the late 1960's and 1970's, separate programs and retreat experiences for individuals with IDD developed around the country, which for the most part were self-published and shared informally.⁸⁸ However, it's important to remember, these were typically intended for individuals with a more significant level of ID, moderate, severe, or profound. Individuals with a mild level typically attended the general parish catechetical program. However, regardless of cognitive abilities, pastoral leaders should expect the ability for spiritual growth. Various models for religious education and spiritual development for persons with ID developed during this time.⁸⁹

Two multidimensional programs developed then, that still exist, are Special Religious Education Division (SPRED) and Religious Education and Activities for the Community Handicapped (R.E.A.C.H.). They provide adapted religious education and liturgies, and one also includes social activities and sometimes service outreach. SPRED began in the Archdiocese of Chicago and R.E.A.C.H. in Topeka, KS. Both were based on the social nature of human beings, which requires participation in a community for a meaningful life, including faith.⁹⁰ Sister Mary Therese Harrington, S.H. of SPRED, spoke of the importance for parishes to have an invitational attitude towards individuals who lived in institutions, that families should sponsor individuals to foster connection and participation in the parish. "No big busses dropping off a crowd," she said.⁹¹ Recreational opportunities should be provided through collaborative efforts of

⁸⁸ Michelle N. Baum and Janice L. Benton, "The Evolution and Current Focus of Ministry with Catholics with Disabilities within the United States," *Journal of Religion, Disability & Health* 10, no. 1-2 (2006): pp. 42-46.

⁸⁹ For further information, see: Janice LaLonde Benton and Mary Jane Owen, eds., *Opening Doors to People with Disabilities* 3vols., vol. II A and II B, Opening Doors (Washington, D.C.: NCPD, 1995). Another very rich source of information is the *NAMR*, the journal for the National Apostolate for the Mentally Retarded.

⁹⁰ Sister Mary Therese Harrington, S.H., "A Community of Believing People," *NAMR Quarterly Publication* 4, no. 2 (1972): pp. 16-17; Dolores Lebbert, "R.E.A.C.H.: Religious Education and Activities for the Community Handicapped," *ibid.* 6, no. 3 (1975): pp. 12-13.

⁹¹ Sister Mary Therese Harrington, S.H., "President Views," *ibid.*, no. 1.

individuals from the network of parishes.⁹² There are subtle differences between the two programs. But what is most interesting is that they both expressed the ultimate purpose of full and integrated participation within the full parish community, yet to this day have not been able to achieve this.

The past few examples paint some conflicting messages and frameworks. Yet a consistent call was to undermine the belief that individuals with IDD are 'holy innocents,' with no need for the sacraments. NAMR tried to promote a general theological anthropology that includes individuals with disabilities and that all people are equally called to holiness through baptism, but already some disconnections are evident. For now, however, I will simply present highlights of its first conference, *The Spiritual Equality of All God's Children* 1971, which attempted to resolve this issue again, though not for the last time.

The time has come to dispel the erroneous belief that the retard are the Holy Innocents of God's creation. This myopic view of a retarded person has too often allowed the religious educator to assess the learning potential of his students without the knowledge of their developmental potential, without realization that they have the ability to assimilate material once considered too abstract for their limited cognition.⁹³

This is a fairly serious accusation about the qualifications of the catechists and even the integrity of at least some of the programs. To achieve NAMR's purpose, the conference addressed three specific dimensions of catechesis: the faith to be communicated; the person communicating the faith; and the person receiving the faith. The caliber of the speakers is impressive, a theologian and a psychologist who taught in seminaries, a nationally respected archdiocesan supervisor of special education services who had written catechetical materials for children with intellectual disabilities and their catechists, and a public administrator. All the speakers challenged sentimental

⁹² Ibid.

⁹³ Fr. Joseph C. Gengras, "Just Five Words," *ibid.* 3 (1971): p. 4.

stereotypes of individuals with IDD and called for authenticity in message, motivation, and method of catechesis.⁹⁴ This message is as relevant today as it was then.

Both McBrien and McCall stressed integrity and qualification for the role of catechist. McBrien cautioned that desire for the task should not be confused with the ability to do the task, and if unqualified for the task, people are often apt to share “their own unresolved conflicts and hidden prejudices.”⁹⁵ McCall also cautioned against “unconscious psychological and emotional needs of persons which might motivate them to teach religion to the mentally retarded.”⁹⁶ He also reinforced the need for self-awareness, to recognize if they were doing anything that restricted social and emotional development, which undermines Christian formation. If so, the religious educator must reassess their motivations, attitudes and consequent behavior in conjunction with the interpersonal relationship quality.⁹⁷ “The Person Communicating the Faith” said McCall, “should be a mature Christian of generous spirit, capable of developing relationships which stimulate “awareness, that God is present among us ... The interpersonal communion between the teacher and student is a sacramental encounter with Christ which makes the religious experience real and concrete.”⁹⁸

On the faith to be communicated, McBrien challenged catechists to be willing to always critically self-assess the image of God they presented. Did it give life or stifle growth? Did they teach that God “actually sends misfortune so we can save our

⁹⁴ John DeLeo, "Conference Report," *ibid.*: 7-15. Fr. Richard McBrien, Fr. John McCall, S.J., Sister Mary John Minetta, S.H.F., and Arthur DuBrow from the Department of Health in CT.

⁹⁵ Fr. Richard McBrien, "The Faith to Be Communicated, Author's Notes," in *The Spiritual Equality of All God's Children* (Passionist Monastery, West Hartford CT: University of Notre Dame Archives, 1970), pp. 2-4.

⁹⁶ DeLeo, "Just Five Words," p. 13.

⁹⁷ *Ibid.*, p. 14.

⁹⁸ *Ibid.*, pp. 12-13.

souls?”⁹⁹ He cautioned such negative images of God that fostered parents to “adjust to their ‘*misfortune*,’ feeling guilt and anxiety that they are being punished for some past sin.”¹⁰⁰ Rather, McBrien said, God is “the God of love ... of mercy ... of justice ... allow[ing] people to behold a hopeful future.”¹⁰¹

Sister Mary John, S.H.F. Arthur DuBrow spoke of the importance for full respect of the person receiving the faith in age appropriate ways, and not treating adults as children. Also, the importance of appropriate methods of communication and engagement was emphasized. Methodology should recognize and respect the potential for individuals with intellectual disability to not only learn, but also assimilate principles of faith and spirituality that had once been considered beyond their ability.¹⁰²

The keynotes caused a bit of consternation and generated much discussion amongst the attendees. They were particularly stretched by McBrien and McCall, but all would require further thinking.¹⁰³ These are tough issues to penetrate, and four years later, Fr. Thomas Cribbin, from the Diocese of Brooklyn, was still challenging the isolation of individuals with ID through labeling as, ‘special,’ ‘different,’ or ‘other people,’ which denies their essential dignity as a person.¹⁰⁴ And still, this is a concern today and at the heart of this thesis.

3. Normalization Principle and Institutions

During the 1970’s long established biases and practices regarding individuals with IDD were being challenged in the broader landscape of American society. Wide

⁹⁹ Ibid., p. 11.

¹⁰⁰ Ibid.

¹⁰¹ Ibid. The word “man” was changed to “people” in the quote for gender neutrality.

¹⁰² Ibid., p. 14.

¹⁰³ Ibid., pp. 7-15.

¹⁰⁴ Fr. Thomas R. Cribbin, “Born Free????,” *ibid.* 6, no. 3 (1975): pp. 21-22. Fr. Cribbin was the Director of Catholic Charities Office for the Handicapped there.

scale institutionalization with its dehumanizing practices were coming under fire, as well as the preclusion of individuals with disabilities to live as other people live, making choices, earning a living wage, having relationships and a home, even making mistakes.¹⁰⁵ I will briefly refer to the work of three people in particular, Bengt Nirje, Wolf Wolfensberger and Robert Perske, who were working on models to address the horrors of the first to provide access to the latter, with their pivotal roles in reshaping mindsets,.

During the 1960's there were a series of newspaper exposes which led to the 1970's litigations and live expose of Willowbrook State School on Staten Island, New York by Geraldo Rivera produced by ABC. The exposes of the 60's showed the horrific conditions that individuals with IDD lived in. Senator Robert Kennedy visited in Willowbrook in 1965 and called it a "snake pit," and also in the photo essay, *Christmas in Purgatory* in 1965 by Fred Kaplan.¹⁰⁶ It housed 6,000 people in a facility intended for 4,000, although it would be another seven years before anything was done about it,¹⁰⁷ only after Rivera's infiltration. However, it was not an isolated issue of degrading individuals with intellectual disability. Approximately 200,000 individuals with IDD were housed in institutions in 1960. In 1964 the per diem rate to take care of them was \$5.57 per day, roughly half of what was spent at that time to take care of animals in a zoo. In fact, on a tour by Swedes and Danes of institutions in the US they remarked that their countries treated cattle better than the US treated people with IDD.¹⁰⁸

¹⁰⁵ Minnesota Governor's Council on Developmental Disabilities, "The Fight for Civil Rights for People with Disabilities"; The Keystone Institute, "An Introduction to Social Role Valorization: A Framework for Assisting People to Have Full, Rich and Meaningful Lives: A Comprehensive SRV Workshop," ed. Elizabeth Neuville (Harrisburg, PA March 2018), Day1.

¹⁰⁶ Schalock and Wehmeyer, "The Parent Movement: Late Modern Times: 1950 CE to 1989 CE," pp. 222-228.

¹⁰⁷ Minnesota Governor's Council on Developmental Disabilities, "The Fight for Civil Rights for People with Disabilities".

¹⁰⁸ Ibid.

Wolf Wolfensberger called attention to the atrocities of institutionalization of the 20th century in *The Origin and Nature of Our Institutional Models*, traveling their development in time. The first institutions of the mid-19th century were typically located near town centers, expecting that they could educate “feeble-minded” individuals and return them home. However, towards the latter part of the century, they changed function from education or training to sanctuary or shelter and were called hospitals. Pity transitioned to benevolence, Wolfensberger said, before it devolved into brutality, perhaps out of resentment “they” did not “get well,” and its new purpose was to protect society. He identified three trends operative in marginalizing groups of people: isolation, enlargement and economization.¹⁰⁹

The work of Wolfensberger and others addressing the institutional warehousing of human beings provides context to understand the social dynamics during this time. It is important to know this was going on while the US Catholic Church was working out its own understanding of disability, theology and pastoral practice. Yet, these were not parallel tracks. Wolfensberger, as a Catholic and Perske as a Presbyterian chaplain, engaged with NAMR, as well as impacted the general landscape regarding individuals with IDD in congregational and community life, as ecumenical and interfaith collaboration was very common in the early years. In general, there was a diversity of approaches and perspectives relative to ministry with persons with disabilities, even though they all said they were working for the same thing, full and meaningful participation. Wolfensberger and Perske challenged the segregated and multidimensional models mentioned so far with a very different model and framework, and Wolfensberger would do so more ardently as the years went on.

Wolfensberger studied with Bengt Nirje on his normalization principle in Toronto, where he was the Coordinator of Training for the Ministry of Health of the Ontario Government and Wolfensberger was a Visiting Scholar at the National Institute on

¹⁰⁹ Wolf Wolfensberger, *The Origin and Nature of Our Institutional Models* (Syracuse, ny: Human Policy Press, 1975), pp. 23-33. Wolfensberger was a contributing author on this subject for the President’s Commission on Mental Retardation, “Changing Patterns in Residential Services for the Mentally Retarded in 1969.

Mental Retardation in Toronto, Canada.¹¹⁰ In the early 1970's Perske advanced the idea that risk-taking is a dimension of human dignity and that, "clever ways of building the avoidance of risk into the lives" of people with ID that stunted their personal development, and indeed, there is a "dehumanizing indignity in safety."¹¹¹

Wolfensberger introduced Bengt Nirje's normalization principle in the United States. It was a revolutionary model which suggests that individuals with IDD should be able to participate in life events and activities in normal patterns, like society in general. Nirje had improved on the work of Niels Erik Bank-Mikkelsen in Denmark who posited that individuals with disabilities be allowed "to obtain an existence as close as possible to that of the normal."¹¹² Nirje's model intended to clarify the focus was on access to typical patterns of life, to do things in ordinary ways. They should also have the opportunity to make decisions for themselves. However, it often struggled against the impression it was trying to normalize *people*, as if to take away their disability and make them fit in to the dominant culture.¹¹³ Building on the importance of *typical patterns of life*, Perske, Executive Director of Greater Omaha Youth Association for Retarded Citizens, promoted the "dignity of risk," based on the importance of making decisions for oneself. Learning this, he posited, required the opportunity to develop the skill, which everyone should have the right to do and the opportunity to take risks and even fail.¹¹⁴

¹¹⁰ Wolf Wolfensberger et al., *The Principle of Normalization in Human Services* (Toronto: National Institute on Mental Retardation, 1972; repr., "The Principle of Normalization In Human Services" Books: Wolfensberger Collection. 1.), Biographical Notes.

¹¹¹ Robert Perske, "The Dignity of Risk and the Mentally Retarded," (1972): p. 5-6.

¹¹² Minnesota Governor's Council on Developmental Disabilities, "The Fight for Civil Rights for People with Disabilities".

¹¹³ Roos and McCann, "Major Trends in Mental Retardation," p. 8; The Keystone Institute, "An Introduction to Social Role Valorization: A Framework for Assisting People to Have Full, Rich and Meaningful Lives: A Comprehensive SRV Workshop," Day1.

¹¹⁴ Minnesota Governor's Council on Developmental Disabilities, "The Fight for Civil Rights for People with Disabilities".

Nirje, as the Executive Director for the Swedish Association for the Mentally Retarded, had developed a club for adults with IDD based on his normalization principle in Sweden in 1969, and the adults the group was for ran it..

The Greater Omaha Youth Association for Retarded Citizens (GOYARC) had been organizing large youth rally meetings, with groups of typically developing teens serving teens with disabilities. Through Perske's work with Nirje, they knew about the club for adults with IDD that he had developed based on the *normalization principle*, the teens recognized a conflict in the group's purpose and the experiences of the youth group, so the members decided to follow Nirje's model. They drastically changed its name, structure, and purpose, and began with a pilot, limiting each group size to 20, half and half, typically developing teens and teens with IDD. All members planned group and activities. Everyone was welcomed as they were, and did not have to contribute in a particular way, but were able to simply be, and contribute what they could and wanted to.¹¹⁵

The change transformed the dynamics significantly. Its new name became Small Core Youth Groups. Many groups sprung up around town after the initial pilot that lasted 5 months. Voluntary comments describing the new groups by their members revealed closer relationships and attitude transformation away from charity, or being protectors. Bonds were formed among group members at a level that is difficult to do within the large service model.¹¹⁶ The approach they followed was designed for success from the beginning. They identified a successful model to work from, studied, and then developed their new group *slowly*, methodically, and also significantly, kept the group, and all future ones, small. The approach will come up again and be good to remember.

The difference is described well by Kris Petersen, the President, "There is a gap in respect and concern when a group of youths sees itself as 'serving' other youth – as doing things for them rather than with them. There will continue to be two groups: ...

¹¹⁵ Bob Perske, "Some Hints toward Developing Small Core Youth Groups," *NAMR Quarterly Publication* 6, no. 2 (1975): p. 17.

¹¹⁶ *Ibid.*, pp. 18-19.

Without a change in focus, there would always be a them and us.”¹¹⁷ This is an example of what ministry with persons with disabilities is working for and what the *Pastoral Statement* will be speaking about.

Nirje, Wolfensberger and Perske made a significant impact on support service systems for and thought about individuals with IDD, contributing much to what is now part of person-centered planning that seeks to increase the quality of life of individuals with IDD. The insights of their work from the 1970’s will be discernable in the *Pastoral Statement* coming up.

C. Pastoral Statement of the U.S. Catholic Bishops on Persons with Disabilities

The *Pastoral Statement of the US Catholic Bishops on Persons with Disabilities* is the essential presentation of theology and disability for the US Catholic Church, and it is the definitive source for any further US ecclesial documents that reference persons with disabilities, whether exclusively or as part of a larger conversation. It was prophetic in 1978, when first promulgated, and it continues to be so to this day. The language used to reference persons with disabilities was updated in 1989 and 1998 to maintain relevancy.¹¹⁸ As its name indicates, the document is pastoral in nature, just as Vatican Council II was, and essentially builds on its work, particularly the *Pastoral Constitution*. Accordingly, the US Bishops speak as pastors, with the collegial authority of a Bishops’ College.

¹¹⁷ Kris Petersen and Patrick Henry, "Youth Core Groups: To Bring People Closer," *ibid.*, no. 1: p. 7.

¹¹⁸ USCCB, "Pastoral Statement of the U.S. Catholic Bishops on Handicapped People," (Washington, DC: USCCB, 1978); "Pastoral Statement of the U.S. Catholic Bishops on People with Disabilities," (Washington, DC: USCCB, 1978; reprint, 1989, Updated language); "Pastoral Statement of the U.S. Catholic Bishops on Persons with Disabilities," (Washington, DC: USCCB, 1978; reprint, 1998). The first shift was to person-first language in the text title and body, the second shift was to acknowledge the diversity amongst individuals with disabilities, which is reflected in the shift from ‘people’ to ‘persons’ in the title. However, due to some editorial problems with the 1998 edition that will be discussed later in the chapter, the 1989 reprint edition will be quoted unless otherwise noted.

The same Jesus who heard the cry for recognition from the people with disabilities of Judea and Samaria 2,000 years ago calls us, His followers, to embrace our responsibility to our own disabled brothers and sisters in the United States. The Catholic Church pursues its mission by furthering the spiritual, intellectual, moral and physical development of the people it serves. As pastors of the Church in America, we are committed to working for a deeper understanding of both the pain and the potential of our neighbors who are blind, deaf, mentally retarded, emotionally impaired, who have special learning problems, or who suffer from single or multiple physical handicaps—all those whom disability may set apart. We call upon people of good will to reexamine their attitudes toward their brothers and sisters with disabilities and promote their well-being, acting with the sense of justice and the compassion that the Lord so clearly desires. Further, realizing the unique gifts individuals with disabilities have to offer the Church, we wish to address the need for their integration into the Christian community and their fuller participation in its life.¹¹⁹

The first paragraph is pregnant with implications. It sounds an alert to the Church, discloses its function, makes a promise, gives a call to action and issues a challenge. I have organized these five directives into three categories to highlight its key points and provide a framework for its discussion: shared human dignity and responsibility; acknowledging prejudices and injustice; responding with justice and compassion.

1. Human Dignity and Responsibility

The interconnection of ecclesial identity and action has already been noted, and the *Pastoral Statement* begins with an essential part of the Church's function and mission: to support the development of its people spiritually, intellectually, morally and physically. Next, the opening alert comes directly from Jesus to all Christians for accountability to recognize their brothers and sisters with disabilities, just as he did 2000 years ago.¹²⁰ This historical reference notes continuity with Jesus' ministry, and clarifies that their call for recognition expresses the feeling of isolation and marginalization from the Christian community and beyond.¹²¹ The Christian responsibility is to recognize

¹¹⁹ "US Pastoral Statement," par 1.

¹²⁰ Ibid.

¹²¹ Ibid., par 4. 4

people with disabilities, not fix them. Recognizing someone is to acknowledge them, to appreciate them for who they are, and to understand them, or at least work to understand them.¹²²

The *Pastoral* provides a basic understanding of disability that locates it within the core principles of Catholic Social Teaching. In other words, disability is part of being human, rather than some separate category. After the alert comes a declaration of purpose or mission, which is to support the full development of all people. This reinforces the common humanity of all people, regardless of ability or disability. Then, as pastors, promising, to correct the past collective dereliction by “working for a deeper understanding of both the pain and the potential ... of all those whom disability may set apart.”¹²³ This promise acknowledges not only the lack of understanding by the Church about the impact of disability on the lives of individuals and families, but also to its lack of appreciation of what individuals with disabilities are capable of.

The bishops recall *Gaudium et Spes* as they frame the Church’s response to persons with disabilities, which is based in its communal identity, projecting the vision of the Church as ‘a community of interdependent people’, in which there is a Christian duty to foster a culture that recognizes human dignity and supports personal development which fosters responsible collaboration for the common good. Citing *Pacem in Terris* explicitly, which is also heavily referenced in this section of *Gaudium et Spes*, this personal development is a right based on human dignity.¹²⁴ Further, the reason for this love is not to do nice things and build up points to go to heaven, it is based on our shared humanity.

We all struggle with life. We must carry on this struggle in a spirit of mutual love, inspired by Christ's teaching that in serving others we serve the Lord

¹²² Random House Unabridged Dictionary Online, "Dictionary.Com," Dictionary.com, <https://www.dictionary.com>. "Recognize." <https://www.dictionary.com/browse/recognize?s=t> accessed 4/23/2020.

¹²³ USCCB, "US Pastoral Statement," par 1, 6.

¹²⁴ Council Fathers of Vatican II, "Pastoral Constitution, Abbott," L6301-6317.

Himself. (cf. Mt. 25:40) In doing so, we build a community of interdependent people and discover the Kingdom of God in our midst.¹²⁵

In acknowledging that all people struggle with life, yet the struggles are not neutralized, thereby diminishing the significant struggles that many persons with disabilities live with, which is not helpful. But it does acknowledge that we are all vulnerable and that the way to overcome this vulnerability is only through mutual love, as Christ taught us, to serve each other. In so doing we are serving Christ. However, this is not a one-way transaction, but occurs within an intricate web of relationships that develop an *interdependent* people.

Interdependent people receive from others, as well as give. It requires the admission of need for others, as well as the need to change. The bishops foretell that local churches will discover the Kingdom of God in its midst when people open themselves in this way to change and become a community where all are truly welcomed, valued and nourished as disciples of Christ. This requires a respect for life that works in justice and compassion to celebrate all of life and support full human development to the extent possible of individuals with disabilities. However, there is still much work to do, as the bishops issue a challenge, because something is preventing the justice and compassion called for.

2. *Prejudice and Attitudes*

The bishops challenge “people of good will to reexamine their attitudes toward people with disabilities and promote their well-being, acting with a sense of justice and compassion toward their brothers and sisters with disabilities that the Lord so clearly desires,”¹²⁶ This recalls Vatican II, but more specifically, Pope John XXIII, in *Pacem in Terris*, speaking to the world about the inalienable rights of all human beings as

¹²⁵ USCCB, "US Pastoral Statement," par 5.

¹²⁶ Ibid., par 1.

persons.¹²⁷ With this reference to *Pacem in Terris*, human dignity is declared the basis for personal rights, without having to say the words specifically.

Prejudice starts with the simple perception of difference, ... Down through the ages, people have tended to interpret the differences in crude moral terms. *Our* group is not just different from theirs; it is better in some vague but compelling way. Few of us would admit to being prejudiced against people with disabilities. We bare them no ill will and do not knowingly seek to abrogate their rights. Yet people with disabilities are visibly, sometimes bluntly different from the norm, and we react to this difference. Even if we do not look down upon them, we tend all too often to think of them as somehow apart – not completely *one of us*.¹²⁸

This points to the power dynamics of devaluation that leads to the marginalization of groups of people, which contradicts the responsibility to love one's neighbor as oneself.¹²⁹ As oneself is an important qualifier, because charity or justice is not authentic unless based on sincere love and understanding "that penetrates the wall of strangeness to affirm the common humanity underlying all distinction. ... We must love others from the inside out, so to speak, accepting their difference from us in the same way that we accept our difference from them"¹³⁰ With such genuine love, disability and difference are not neutralized or denied, but are recognized and accepted in the same way we wish our own differences to be accepted.

3. Call to Action

Once attitudes have been examined and adjusted, the Church and in fact, all people of goodwill, are to respond with justice and compassion "to promote their well-being," recognize their gifts, and work for their integration and fuller participation into community and parish life.¹³¹ And it must be remembered that this call to action comes

¹²⁷ Pope John XXIII, "Pacem in Terris."

¹²⁸ USCCB, "US Pastoral Statement," par 2.

¹²⁹ Ibid., par 3.

¹³⁰ Ibid.

¹³¹ Ibid., par 1.

from Jesus to all Christians, to embrace their responsibility to their brothers and sisters with disabilities in the United States.

The bishops have some pretty bold ideas about the possibilities this could bring about. Speaking directly to the parish environment, "Institutionalization will gradually become less necessary for some as the Christian community increases its awareness of disabled persons and builds a stronger and more integrated support system for them."¹³² Also, "It is not enough merely to affirm the rights of people with disabilities. We must actively work to make them real in the fabric of modern society."¹³³ The bishops' words demonstrate the impact that natural relationships can have on individuals, especially on those who are used to being marginalized and ignored. This statement provides a powerful image of persons with disabilities being fully integrated within society, just as the threads of a fabric are interwoven within the whole. Both of the sentences highlight the Church's responsibility to influence social policy and structures that support human flourishing, echoing the intentions of Vatican II.¹³⁴

However, the *Pastoral Statement* goes even further, by saying the Church needs to reach out to persons with disabilities actively to participate within the parish community because, "The Church finds its true identity when it fully integrates itself with these "marginal people," including those who suffer from physical and psychological disabilities."¹³⁵ Although the sentence sounds a bit like *us* and *them*, the implications are significant. It goes way beyond making space in a pew for someone to sit. It goes beyond integrating someone *into* the Church, which presumes tolerance, yet need for

¹³² Ibid., par 10. Bracketed text replaces dated reference to persons with disabilities.

¹³³ Ibid., par 11.

¹³⁴ Council Fathers of Vatican II, "Message to Humanity, Abbott."; NCCB, "Proposed Action Item Amendment: Pastoral Statement on Handicapped People," (1978). Two bishops, Thomas Costello and Edward Head suggested additions that noted the integrated support systems of a Christian community could gradually lead to reduced need for institutionalization.

¹³⁵ USCCB, "US Pastoral Statement," par 12.

the *other* to change. Integrating *oneself with* others suggests mutuality and reciprocity that also requires the development of a new identity. Wolfensberger's influence is clearly discernable here in this and the section noted above.

Parish life is the entrance to the experience of Christian community, so pastors and other pastoral leaders are to ensure that all participating in parish life is accessible to persons with disabilities. This will often be very simple, they say, but at other times will require ingenuity and wide collaboration within the parish, "in order to be loyal to its calling, to be truly pastoral, the parish must make sure that it does not exclude any Catholic who wishes to take part in its activities."¹³⁶ Fulfilling this will require working with individuals with disabilities and their families to ascertain their needs and interests, as well as educating parishioners about the rights and needs of individuals and families living with disabilities.¹³⁷

The bishops repeatedly claim the interconnection between identity and action, this is part of the Church's identity as the people of God, the Body of Christ. Further pointing to the Church's identity, "To exclude members of the parish from these celebrations of the life of the church, even by passive omission, is to deny the reality of that community."¹³⁸ This includes more than physical changes to ecclesial spaces and includes all forms of liturgy, which refers to all moments of corporate worship, including celebrations of the sacraments, because liturgical celebrations are central to the spiritual interconnection of the Church.¹³⁹

Consistent with the desire to facilitate meaningful participation within the full parish community, the *Pastoral Statement* clarifies that integrated participation means being together in liturgy. During the editing process they changed, "develop worship services in which they can take an active part," to "make those liturgical adaptations

¹³⁶ Ibid., par 18.

¹³⁷ Ibid., par 19, 20.

¹³⁸ Ibid., par 23.

¹³⁹ Ibid.

which promote their active participation.” The final version of the text presumes the ability of someone with a disability to participate in liturgy and the full life of the Church with appropriate support, rather than needing an alternative environment. Another suggestion enhanced this as well, by changing “simple aids and training” to “proper aids and training” in paragraph 24. Bishop Gueida said the first text was patronizing, persons with disabilities “need what would properly help them exercise a role of ministry in the liturgy.”¹⁴⁰ Clearly the normative practice of separate liturgies for individuals with disabilities contradicts the central vision of the *Pastoral Statement*. In general, the bishops call for pastoral sensitivity in adaptations to support full participation in the Church’s liturgical life.

Similar direction is given for catechesis. While adaptations and supports are important, there is the strong directive to avoid isolation of individuals with disabilities from the typical parish catechetical programs.¹⁴¹ The US Bishops were interested in something much more than catechetical programs for individuals with ID. They were concerned with matters of justice and compassion about the rights of individuals with IDD, as persons, to education and nurturing their full development as individuals and disciples of Christ. This commitment is to be motivated by the sincere desire out of charity, to truly love our neighbor as ourselves, with the realization that it is difficult to truly love if we do not understand.¹⁴² True charity requires sincere interest in the other person to be authentic. Unfortunately, charity often labors under the weight of acts simply masquerading as charity, which are really self-serving.

However, the bishops are fully cognizant that these changes won’t come easily. “If people with disabilities are to become equal partners in the Christian community, injustices must be eliminated and ignorance and apathy replaced by increased

¹⁴⁰ NCCB, “Proposed Action Item Amendment: Pastoral Statement on Handicapped People.” Changes suggested by Bishop Gueida for par 23 and 24.

¹⁴¹ USCCB, “US Pastoral Statement,” par 23; *National Directory for Catechesis* (Washington, D.C.: USCCB, 2005), par 49.

¹⁴² “US Pastoral Statement,” par 1, 3, 9, 11, 13, 35.

sensitivity and warm acceptance.”¹⁴³ The bishops admit this will require an emphasis on educating the entire parish as a foundation for successful change.¹⁴⁴ This echoes the Council Fathers in the *Pastoral Constitution*, “If these objectives are to be attained there will first have to be a renewal of attitudes and far-reaching social changes.”¹⁴⁵ Further guidance in this area reinforces the uniqueness of every person with a disability and that they and their family members should be consulted regarding what would be helpful for full and meaningful participation that includes opportunities to serve as well. “Full participation in the Christian community has another important aspect that must not be overlooked. When we think of people with disabilities in relation to ministry, we tend automatically to think of doing something for them. We do not reflect that they can do something for us and with us.”¹⁴⁶ In other words, not only do the bishops point out that individuals with disabilities have the ability to participate in ministry, but they call out the attitude that presumes they do not.

The *Pastoral Statement* spoke to structural supports for the practical concerns of supporting ministry with persons with disabilities. References to the parish was noted earlier in specific quotes and diocesan offices are called to improve efficacy at the parish level, primarily through education, advocacy, clarifying lived applications of policies and keeping up with relevant local public policies. They even raised the need to improve support for students with disabilities in Catholic schools. Collaboration with Catholic and other agencies who support persons with disabilities was recommended to prepare pathways for integration where possible.¹⁴⁷ National support would be provided by the National Conference of Catholic Bishops and the U.S. Catholic Conference from the US Conference, by designating ministry to people with disabilities as a special focus

¹⁴³ Ibid., par 13.

¹⁴⁴ Ibid., par 20.

¹⁴⁵ Council Fathers of Vatican II, “Pastoral Constitution, Flannery,” par 26.

¹⁴⁶ USCCB, “US Pastoral Statement,” par 17.

¹⁴⁷ Ibid., par 27-31.

that was to be included in plans and programs by each office and secretariat. The bishops also promised to “be more vigilant in promoting ministry with persons with disabilities throughout the structure of the Church.”¹⁴⁸

The bishops close the document potently, promoting a strong sense of identity, purpose and promise about persons with disabilities and the Church, together. “People with disabilities are not looking for pity. They seek to serve the community and to enjoy their full baptismal rights as members of the Church ... There can be no separate Church for people with disabilities. We are one flock that serves a single shepherd.”¹⁴⁹ The Church’s resounding affirmation of human dignity is declared, “No one would deny that every man, woman and child has the right to develop his or her potential to the fullest. With God’s help and our own determination, the day will come when that right is realized in the lives of all people with disabilities.”¹⁵⁰

D. The Gospel in Shadow

The *Pastoral Statement of the US Catholic Bishops on People with Disabilities* is a powerful and prophetic representation of Catholic Social Teaching. Yet, the Church still struggles to live this faithfully. The members of NAMR were concerned it lacked sufficient detail for its purpose, particularly that it did not reject segregated programs that isolate individuals with disabilities, nor did it emphasize participation in the full sacramental life of the Church strongly enough.¹⁵¹ However, there was much to be pleased with. Rosemary Dybwad, a Senior Associate from Brandeis University’s Florence Heller Graduate School, was a speaker at the NAMR conference the following year and praised the *Pastoral Statement*. Her presentation emphasized the importance of involving persons with IDD in the general life of the community by using typical

¹⁴⁸ Ibid., par 32, 34.

¹⁴⁹ Ibid., par 33.

¹⁵⁰ Ibid., par 35.

¹⁵¹ Lampe, “The Story of the National Apostolate for Inclusion Ministry,” p. 63.

patterns of community engagement, rather than isolated means.¹⁵² She made an avid and articulate case for Bengt Nirje's normalization principle as the most important new strategy to make a difference, which she noted the *Pastoral Statement* was in agreement with. Included in her discussion was a strenuous call to get "rid of the idea that mentally handicapped people are the 'Holy Innocents,' or Eternal Children' or 'Heavenly Peter Pans.'"¹⁵³

However, not all people were happy with the *normalization principle*. NAMR's President at the time, Sister Bernadette Downes, C.I.J., questioned it in the same issue that covered Dybwad's conference presentation. She wondered if fiscal issues and productivity were the underlying motive, rather than valuing people.¹⁵⁴ I noted before that some people had misconception about Nirje's work. It is one reason why Wolfensberger developed Nirje's work further into Social Role Valorization theory, but it includes other dimensions as well. Wolfensberger's work will provide the organizational framework for the constructive piece of my argument.

1. Some Disappointments

The fact that the *Pastoral Statement* is so rich and dense may be one of its greatest weakness. However, there are some notable omissions revealed in the bishops' discussions of the document and some vague language which has undermined its strength. The implications of these shortcomings will become apparent in the discussion of ministry development.

The *Pastoral Statement* directly anchors the document in *Pacem en Terres* and human dignity, "On the most basic level, the Church responds to persons with

¹⁵² Rosemary Dybad, "Parish Awareness – International Developments and Voluntary Associations for the Mentally Retarded," *NAMR Quarterly Publication* 10, no. 3 (1979): pp. 5-7.

¹⁵³ Ibid.

¹⁵⁴ Sister Rosemary Downes, C.I.J., "The President's Views," *ibid.* Interestingly, she wrote this in the same issue as Dybad's article above, presenting a different perspective on the normalization principle.

disabilities by defending their rights. Pope John XXIII....stresses the innate dignity of all men and women. .."it is a fundamental principle that every human being is a 'person' ... [One] has rights and duties ... flowing directly and spontaneously from [one's] very nature. These rights are therefore universal, inviolable and inalienable."¹⁵⁵ Yet, it equivocates and falls short of the bar established by Pope John and the Council Fathers in respect for human dignity.

Paragraphs 10 and 11 positively emphasize the need to work for persons with disabilities to be active within society and that the right to life implies right to achieve fullest measure of personal development. But then they dilute this when they decide to say, "All people have a clear duty to do what lies in their power to improve *living conditions* for people with disabilities, rather than ignoring them or attempting to eliminate them as a burden not worth dealing with,"¹⁵⁶ instead of "improving *quality of life* ...," which Bishop George Evans suggested. The bishops were concerned it would negatively impact the Right to Life focus.¹⁵⁷ It was not clear from their comments what the concern was, but certainly quality of life issue is part of respecting life and would have strengthened the professed belief in human dignity of persons with disabilities.

Bishop Thomas Costello tried to strengthen the commitment of the bishops that individuals with disabilities achieve the "fullest measure of personal development" in two ways.¹⁵⁸ First, he suggested deleting the word "'decent' from 'decent quality' personalized care." Second, by adding "Institutions will gradually become less necessary for some as the Christian community increases its awareness of the handicapped and builds a stronger and more integrated community support system for them." Instead "quality" was deleted in his first item and his second item was modulated

¹⁵⁵ USCCB, "US Pastoral Statement," par 7.

¹⁵⁶ Ibid., par 9.

¹⁵⁷ NCCB, "Proposed Action Item Amendment: Pastoral Statement on Handicapped People." Rejection #12, submitted by Bishop George Evans.

¹⁵⁸ USCCB, "US Pastoral Statement," par 10.

by saying that institutions would become less necessary for “some” and the word “community” was left out.¹⁵⁹ The changes to the last sentence may not be as problematic, as it’s addition is still helpful, but suggesting that “decent care” sufficiently respects human dignity provides no basis for assessment. I noted before that Wolfensberger’s influence was noticeable in the *Pastoral Statement*. This is another subject he spoke of, the importance of natural relationships in people’s lives within smaller settings over institutionalized ones in larger, ‘more efficient’ systems. Wolfensberger was in Syracuse since 1973 and knew Costello very well.

Individuals with IDD have been treated horrifically, and the inhuman conditions of institutionalization already recounted was not the extent of it. There were court cases going into the 1980’s against doctors withholding treatment from infants born with intellectual disability that were so prevalent they had a name, the “Baby Doe” cases.¹⁶⁰ Ambivalence and devaluation continued towards persons with intellectual disabilities, however, regardless of legislation and such public outcries.

Although the commitment by the Bishops’ Conference to provide national support, as already noted, is significant, they intentionally did not promise to establish an office specifically devoted to ministry with persons with disabilities. This was not simply an oversight, because they rejected Bishop James Rausch’s suggestion to do so, which is odd given that a national office was established just four years later, the National Partnership on Disability (NCPD).¹⁶¹ Bishop Lyons gained some broad support for individuals with disabilities by his successful addition of the mandate for all the offices and secretariats of the Bishop’s Conference to address the needs of persons with disabilities in its development of plans and programs, but this would be short-

¹⁵⁹ NCCB, "Proposed Action Item Amendment: Pastoral Statement on Handicapped People."

¹⁶⁰ Schalock and Wehmeyer, "The Parent Movement: Late Modern Times: 1950 CE to 1989 CE," pp. 222-228.

¹⁶¹ NCCB, "Proposed Action Item Amendment: Pastoral Statement on Handicapped People."

lived.¹⁶² His paired suggestion was rejected to include the ministry with the other focus areas of evangelization, pro-life, and “women’s concerns”.¹⁶³ While the mandate for support was an important addition, it was not enough to provide consistently attentive support for individuals with disabilities.

The omission is at the heart of a sense of outsider status that persists to this day relative to the US bishops’ awareness of persons with IDD. Five years after NCPD was established, Sister Rita Baum, it’s first Executive Director, shared such concerns with NCPD’s Board of Directors. Despite positive connections with individual staff members, she reported that “several administrative decisions and actions express ignorance or apathy or rejection of the people we represent.”¹⁶⁴ There was also concern about a general lack of consulting NCPD by the USSC/NCCB concerning issues related to persons with disabilities, such as not discussing possible implications of pursuing exemptions for the American with Disabilities Act.¹⁶⁵

It is quite ironic that while the bishops obtained these exemptions, the *Pastoral Statement* actually influenced its passage, with Senator Tom Harkin quoting it from the Senate floor,

Defense of the right to life implies the defense of other rights which enable the individual with a disability to achieve the fullest measure of personal developmentThese include the right to equal opportunity in education, in employment, in housing, as well as the right to free access to public accommodations, facilities and services. Passage of this bill will mean

¹⁶² Ibid.

¹⁶³ Ibid.

¹⁶⁴ NCPD Archives, "Executive Board and Board of Directors Meeting Notes," 6/1/1987 letter from Sister Rita to the Board.

¹⁶⁵ Ibid., November 2-3, 1989 Executive and Board Meeting notes.

discrimination solely on the basis of handicaps will be not only immoral but illegal.¹⁶⁶

Further indication of such gaps was noted in a report on the New Evangelization guide. It said, "Do not inquire if household has any *handicapped* unless you have facilities to assist them."¹⁶⁷ The sentiment is bad enough, but it also reflects ignorance of the change in language which was instituted in the 1989 revised edition of the *Pastoral Statement*. It also severely waters down the explicit promise in it and introduces a pragmatic shadow on the Gospel. Both of these examples undermine moral chastisements the US Bishops make to governments about quantifying relative value on human life.¹⁶⁸

Another example of this outsider status are ecclesial statements that mention individuals with disabilities only peripherally or in stereotypically constricted ways. A recent one is the working document for the 2018 Synod of Bishops on Young People, the Faith and Vocational Discernment reflects little understanding about living with disability. Although rightly noting the discrimination that individuals with disabilities often deal with, the fact of disability only juxtaposed with sickness, disease, loss, and suffering. Disability therefore is not part of the spectrum of what it means to be human. The only positive reference to individuals with disabilities is a testament to their strength and valor by how they live with their disability and for the opportunity they provide their peers to give them support. Correctly noting the marginalization of individuals with disabilities, it is again linked with sickness, and the lone example of creativity provided

¹⁶⁶ Baum and Benton, "The Evolution and Current Focus of Ministry with Catholics with Disabilities within the United States," p. 49; Janice LaLonde Benton and Mary Jane Owen, eds., *Opening Doors to People with Disabilities* 3vols., vol. II B, *Opening Doors* (Washington, D.C.: NCPD, 1995). Harkin quoted from par. 10 of the *Pastoral Statement*.

¹⁶⁷ NCPD Archives, "Executive Board and Board of Directors Meeting Notes," November 7-8, 1991.

¹⁶⁸ Michele Boorstein, "Catholic Bishops Call Trump's Asylum Rules 'Immoral,' with One Suggesting 'Canonical Penalties' for Those Involved," *Washington Post*, June 13 5:59 pm EDT 2018; CNA Staff, "Following Trump's Halt to US Immigration, Bishops Call for Solidarity," *CNA*, April 24/ 5:13 pm MT 2020.

is “innovative paths to integrate young HIV or AIDS patients into youth pastoral care.”¹⁶⁹ Although calling for the Church to reject and counter the discrimination of individuals with disabilities, the document is not suggestive of how to do this.

The document’s singular perspective on disability as tragedy and its narrow presentation of persons with disabilities is problematic, which does not consider individuals born with a disability. Although the experience of living with disabilities has its difficulties, sometimes quite significant, there is not a loss in ability as happens when someone has an accident. It is unclear why individuals with IDD are not mentioned, but I wonder if it is due to a bias that presumes someone with ID or a developmental disability lacks any true vocation, other than to encourage others to do good. The consistent narrative woven through the three short paragraphs that mention individuals with disabilities is the narrative calling for a false charity that is prompted by pity. Had Bishop Lyons suggestions the ministry be considered a priority concern, this document most likely would have read differently.

Perhaps it would have also prevented the loss of focus that occurred within the Conference when the NCPD was established as an external body and the internal Bishops’ Advisory Committee was dissolved. The bishops explicitly say that the *Pastoral Statement* is “a mandate to each office and secretariat, as it develops its plans and programs, to address the concerns of ... our brothers and sisters with disabilities.”¹⁷⁰ However, when NCPD was established, that stopped. The General Secretary of USCCB, issued a memo stating that, “all ‘special focus’ items have been dropped from plans and programs, but this does not negate the intent of the mandate expressed Please be prepared to give Sister Baum, NCPD’s first Executive Director,

¹⁶⁹ Synod of Bishops, "Working Document: Young People, the Faith and Vocational Discernment," (The Vatican: Vatican, 2018), par 48, 49, 166.

¹⁷⁰ USCCB, "US Pastoral Statement," par 32.

your cooperation as needed in the spirit of the *Pastoral Statement*.¹⁷¹ More than a loss of focus, a promise was broken.¹⁷²

E. Going Forward

1. Structural Challenges

The *Pastoral Statement of the U.S. Catholic Bishops on Persons with Disabilities* proclaims a bold agenda to the Church to be true to its identity and mission as disciples of Christ and to be a place of interdependent people, nurturing full human development of all members to engage fully within the life of the church, as well as in society. The bishops were concerned with matters of justice and compassion about the rights of individuals with IDD, as persons, to education and nurturing their full development as individuals and participation within the Church. This concern for justice is based on the innate dignity of every person, who is created in the image of God, who is love. Therefore, by baptism each person is called to reflect God's love into the world within the details of their lives. The Church is also called to this and has professed it, many times of which have been discussed in this chapter. There really is no need to write any statement of theology on disability and the human person, because the US Bishops did that in their *Pastoral Statement on Persons with Disabilities* in 1978.

However, this is a pattern that will become familiar. The Church issues clear statements of belief that refer to ALL people. Yet somehow, groups of people who are not part of the normative culture are often left behind. So separate statements are proclaimed, saying, in this case, that persons with disabilities are included in the Church's core statements of belief. Then, when individuals with disabilities are still excluded from liturgy and life in the Church, the *Guidelines for the Celebration of the Sacraments with Persons with Disabilities* were finally promulgated in 1995.

¹⁷¹ NCPD Archives, "Executive Board and Board of Directors Meeting Notes," Msgr. Daniel Hoyer, USCC General Secretary. Memorandum to NCCB Executive Directors, USCC Department Secretaries and Secretariat Directors and Office Directors. October 21, 1982.

¹⁷² USCCB, "US Pastoral Statement," par 32, 34-35.

But then again, the message was apparently not clear enough. When the bishops worked on an amendment to the *Guidelines* to simply address new concerns based on issues raised by technology and new health concerns, it became clear that a totally revised edition was needed in 2017, to again amplify the message even more. It reiterates that “full accessibility should be the goal for every parish, and that the adaptations are to be an *ordinary* (emphasis added) part of the liturgical life of the parish”, and as much as possible in catechetical and sacramental preparation programs.¹⁷³ The overall spirit of the *Revised Guidelines* strengthens the call for full and meaningful participation of persons with disabilities in the life of the Church and stresses the importance that “a fully accessible parish reaches beyond mere physical accommodation to encompass the attitudes of all parishioners toward persons with disabilities.” Beyond accessibility is the call for pastoral ministers to notice the gifts of persons with disabilities and encourage them to participate in liturgical and communal ministries and cultivate a true sense of belonging.

Integration, participation and relationship amongst and between all parishioners are emphasized. “All members of the faith community have a role to play in the invitation, welcome, and inclusion of persons with disability.”¹⁷⁴ This call to all members of the faith community adds weight to the repeated call from the earlier version to pastoral ministers to “foster attitudes and parish culture, develop informational materials” toward forming community of believers known for its “joyful inclusion of all God’s people around the table of the Lord.”¹⁷⁵ It focuses attention on the importance of the whole community of faith to effect change. The concluding paragraph informs that the *Revised Guidelines* “are presented to all who are involved in liturgical, pastoral, and catechetical ministry. All persons with disabilities have gifts to contribute to the whole Church. When persons with disabilities are embraced and welcomed, and invited to participate fully in all aspects of parish community life, the Body of Christ is more

¹⁷³ “Revised Guidelines,” par 3, 5.

¹⁷⁴ *Ibid.*, par 7.

¹⁷⁵ *Ibid.*

complete.”¹⁷⁶ And yet, in February 2020 parents are told that their son “didn’t meet the Communion requirement because he is unable to determine right from wrong.”¹⁷⁷

2. *Light Overcome By Shadow*

The real challenge is living it! Everyone, inclusive of individuals with disabilities is created in the image of God, equal in human dignity and called to holiness and participation in God’s work in the world through baptism and it “is a journey in community, side by side with others.”¹⁷⁸ Such a community acknowledges human vulnerability, which is not a weakness. In “Theology and Disability: Changing the Conversation”, Tom Reynolds makes the compelling case that genuine wholeness only comes through accepting our *vulnerable interdependence* within relationships of mutual giving and receiving.¹⁷⁹

Sixty years after the first call for national guidance on ministry with persons with IDD and forty years after the *Pastoral* was promulgated, individuals with disabilities and their families still struggle to find acceptance and a sense of belonging and flourishing consistently within the US Catholic Church. Why? I detected a counter narrative to the Gospel woven throughout the history of ministry with persons with IDD in the US Catholic Church that I named the *shadow narrative* because it dims the light of the Gospel. It has been operative in the rupture between what the Church proclaims and how it lives as the people of God. This does not deny that progress has been made, however the light of the Gospel that would lead to true advancement continues to be

¹⁷⁶ Ibid., Conclusion.

¹⁷⁷ Jorge Fitz-Gibbon, "Nj Family Furious after Catholic Church Denies Autistic Son First Communion," *New York Post*, February 27, 3:53pm, updated 2020.

¹⁷⁸ Pope Francis, "Gaudete Et Exsultate (Rejoice and Be Glad)," (Vatican City: Liberia Editrice Vaticana, 2018), par141.

¹⁷⁹ Thomas E Reynolds, "Theology and Disability: Changing the Conversation," *Journal of Religion, Disability & Health* 16, no. 1 (2012): pp. 39-41.

eclipsed by the multi-faceted and persistent presence of the *shadow narrative* that tells a different story about persons with IDD.

This narrative says that persons with disabilities, particularly IDD are different from “us,” just as the bishops say in the *Pastoral Statement*.¹⁸⁰ I identified five different threads while researching the history of the ministry in the US Catholic Church. The *shadow narrative* is maintained by what Reynolds calls the *cult of normalcy*.¹⁸¹ Examples of the *shadow narrative* abound throughout the history of ministry with persons with IDD in the US Catholic Church, even creeping into ecclesial statements, unaware of the mischief wrought. Before exploring the *growing end* of human dignity¹⁸² and addressing the growing end the *cult of normalcy*, I will cast a light on the five threads of the *shadow narrative* in the next chapter, and follow it’s pervasive presence both in ecclesial documents and in the life of the Church.

¹⁸⁰ USCCB, “US Pastoral Statement,” par 2.

¹⁸¹ Thomas E Reynolds, “Invoking Deep Access: Disability Beyond Inclusion in the Church,” *Dialog* 51, no. 3 (2012); “Theology and Disability: Changing the Conversation.”; *Vulnerable Communion: A Theology of Disability and Hospitality*, (Grand Rapids, MI: Brazos Press, 2008). Kindle

¹⁸² Council Fathers of Vatican II, “Religious Freedom, Flannery,” par 1-2.

III. Shadow Narrative Eclipses The Light

"[T]he more I come to know these people, the worse it is. Because, on the whole, I don't hate them. And some I like. And a lot of them are so damaged that my natural instinct would be to protect them. But all of them must die if I'm to save Peeta."

~ Katnis, Catching Fire, Book 2 of Hunger Games Trilogy by Suzanne Collins

The last chapter explored the history of pastoral activity and ecclesial statements of the US Catholic Church regarding persons with disabilities, searching for reasons to understand why persons with intellectual and developmental disabilities and their families still struggle to find acceptance and a sense of belonging consistently within the Church. This is despite sixty years of intentional pastoral activity on national and local levels with the express purpose to promote full and meaningful participation within it for persons with disabilities.¹⁸³ It is also despite the US Catholic Bishops proclaiming a deeply affirming theology on disability in 1978, more than 40 years ago. This exploration revealed a hidden narrative which contradicts the Catholic Church's affirmative statements regarding human dignity and the presence, participation and flourishing of persons with disabilities within the life of the church. I named this hidden narrative the *shadow narrative*.

In this chapter I hope to cast a bright light on the *shadow narrative* and expose its hidden messages. The fact that the US Catholic Church still struggles with its clearly stated mission regarding persons with disabilities, reinforces the need to understand the dynamics of the *shadow narrative* as well as plans to address it. First, I will define the *shadow narrative* and identify its different threads to illuminate its spectral course throughout ecclesial documents and pastoral activities concerning persons with IDD. Second, I will discuss how the *shadow narrative* marginalizes vulnerable groups of

¹⁸³ "National Apostolate for the Mentally Retarded Constitution Excerpts," *NAMR Quarterly Publication*, no. 1 (1968): pg. 10; NCCB, "Statement on National Office for the Handicapped," (1982).

people. Third, I will point out that this marginalization creates a space referred to as “on the margins” that is often romanticized as a special place to find Jesus. Fourth, I will discuss why a well-known story about a man with profound disabilities has broadcast the sentimental strands of the *shadow narrative*, which has undermined progress for individuals with IDD, even as it brought awareness to them into a more mainstream space. Finally, I will close the discussion on the *shadow narrative* with summary thoughts on the problems created by the *shadow narrative* and share one example of resisting the dominant culture of devaluation that can give food for thought as this discussion goes forward.

A. The Shadow Narrative and Its Five Threads

To briefly recall how I am using narratives, a narrative presents a particular perspective to promote a set of values or vision. A narrative intends to influence others.¹⁸⁴ As noted, I discerned five different narrative threads that together form the one over-arching *shadow narrative*. There are a few different characteristics of a shadow, which makes it a useful reference. It is a dark figure cast over surface or ground that blocks, obscures, conceals, obliterates, overshadows, or eclipses the light, or perhaps only dims the it. Although a shadow can provide relief to summer heat by its shading, within the *shadow narrative* it does not provide relief. Shadows bring periods of gloom, unhappiness, and dissension into relationships. A shadow is a pervasive threat, casting fear and doubt. As shadows hide and conceal, they can portray a false authority, as in a “shadow government.” Shadow also refers to the act of shadowing someone, again, implying stealth, or a specter, when the light is pursued by shadows. Whether standing in the penumbra area of an eclipse in partial shadow, or the umbra area, with light totally obliterated, life is distorted. Animals and plants can be put off balance from the changes in the cycle of light and darkness.¹⁸⁵

¹⁸⁴ Bal, *Narratology: Introduction to the Theory of Narrative*. L 561; Anderson and Foley, *Mighty Stories, Dangerous Rituals*. L 170.

¹⁸⁵ National Geographic, "Solar Eclipse 101," National Geographic, <https://youtu.be/cxrLRbkOwKs>.

While a shadow could be a protective space to hide from danger, it occludes the light of the Gospel in the *shadow narrative*. Light is a source of life, warmth and healing, just as the sun's light is a critical source of heat and energy for all creation.¹⁸⁶ Light is a common scriptural reference to the healing presence of God throughout Isaiah,¹⁸⁷ and to Jesus as the source of light in the world, of the glory of God in the Christian Testament.¹⁸⁸ Pope John XXIII summoned the Second Vatican Council out of fidelity to the Church's sense of attentiveness to the signs of the times in the world, feeling called to "radiate new light," faithful to the image of Christ based on contemporary concerns for humanity.¹⁸⁹ Walter Abbott, S.J., editor of some editions of the Vatican II documents, as well as translator and commentator on some documents, noted that Pope John XXIII named the Light of Christ as the central theme and focus of the Council.¹⁹⁰ The Council Fathers reinforced this in their *Message to Humanity*, stating that through the Council, the Church wished to radiate the features of Christ, "who shines in our hearts" that

¹⁸⁶ "Light," Dictionary.com, <https://www.dictionary.com/browse/light?s=t>.

¹⁸⁷ Katherine M. Hayes, "'The Major Prophets, Lamentations, and Baruch'," ed. Donald Senior; John J. Collins; Mary Ann Getty, Third Edition, Kindle ed., *The Catholic Study Bible: The New American Bible: Revised Edition* (Oxford University Press, USA, 1991). L 176626. God's vision, Isaiah 18:4, God's teaching and judgement, Is 2:1-5; mercy and healing presence, Is 30:26; the Lord's servant is sent to be a "light to the nations", (42:6; 49:6),

¹⁸⁸ 2 Cor 4:4-6, "In their case the god of this world has blinded the minds of the unbelievers, to keep them from seeing the light of the gospel of the glory of Christ, who is the image of God. ... For it is the God who said, 'Let light shine out of darkness,' who has shone in our hearts to give the light of knowledge of the glory of God in the efface of Jesus Christ.'" Mt 5:16, Our good deeds are a light for the world that glorify God; John: "I am the light of the world. Whoever follows me will not walk in darkness, but will have the light of life." 8:12 NRSV

¹⁸⁹ Pope John XXIII, "Pope John Convokes the Council," [Humanae Salutis], ed. Walter M Abbott, Kindle Edition ed., *The Documents of Vatican II: Introductions and Commentaries by Catholic Bishops and Experts, Responses by Protestant and Orthodox Scholars* (New York: America Press Inc., 1966; repr., April 30, 2012). L 17264-17310.

¹⁹⁰ Council Fathers of Vatican II, "Message to Humanity, Abbott." Commentary within fn. 4.

God's splendor may be revealed."¹⁹¹ Further, they hoped that the Council would cause the light of faith to shine more clearly in the world, and initiate a spiritual renewal in human society that would be respectful of all humanity, working for peace based on justice.¹⁹²

The Council Fathers proclaimed within the opening lines of *Lumen Gentium* (*Light of the Nations*), "Christ is the light of all nations and hence this holy synod, gathered together in the holy Spirit, ardently desires to bring to humanity that light of Christ which is resplendent on the face of the church, by proclaiming his Gospel to every creature (see Mk 16:15)."¹⁹³ The point is clear, the light Christ reveals in the Gospel illuminates the path toward human flourishing and harmony on earth. In scripture light indicates Christ's presence providing illumination, healing and knowledge (2 Cor 4:4-6; Lk 2:32, Jn 8:12), and the good works of faithful living that gives glory to God (Mt 5:16).

Yet it is also possible for the light to become corrupted in Christ's followers. "Your eye is the lamp of your body. If your eye is healthy, your whole body is full of light; but if it is not healthy, your body is full of darkness (Lk 11:34-35)." The point here is not to engage in problematic scriptural metaphors, but to note that darkness replaces the light

¹⁹¹ Ibid., L402.

¹⁹² Ibid., L385-436

¹⁹³ Council Fathers of Vatican II, "Dogmatic Constitution on the Church (*Lumen Gentium*)," ed. Austin Flannery, OP, trans. Cornelius Williams, OP and Henry Peel, OP, Kindle ed., 1 vols., *Vatican Council II: Constitutions, Decrees, Declarations: The Basic Sixteen Documents. A Completely Revised Translation in Inclusive Language* (Collegeville, MN: Liturgical Press, 1996; repr., 2014). par. 1.

inside the body, and it is the darkness that is considered unhealthy.¹⁹⁴ As I will share, the *shadow narrative* has inserted itself between the Gospel and persons with disabilities, casting its pall and diminishing or extinguishing its light. This *specter* arises out of outdated assumptions with concealed motives, hidden within unconscious darkness and tells a different story about persons with IDD. It persists to this day, perpetuating the marginalization of persons with IDD within its *pall*.

The *shadow narrative* eclipses the light of the gospel as it comes between the call for full meaningful participation in the life of the church by persons with disabilities and the lived reality in local parishes. The narrative itself casts the shadow, which hides stories of expectations and possibilities about persons with disabilities behind a pretext of love and concern, but which actually undermines their innate human dignity. I have named five different threads, which I consider to be five unique narratives. So, when using a plural indication, I mean the different threads. Sometimes I find them overlapped or intertwined. They are problematic because they are false and devalue and marginalize vulnerable people. For the purposes of this discussion, individuals with IDD. The *shadow narrative* could be considered an overarching meta-narrative, which singularly and together, weaves a tale that diminishes and marginalizes individuals with IDD.

The five threads of the *shadow narrative* are: 1. Persons with disabilities are different because they are forever children, innocent and holy, even called “holy innocents.” They are simple minded and loving, and as such, a refreshing contrast to our fast-paced world that focuses on achievement, power and intellect. 2. Persons with disabilities provide an opportunity for charity and their very presence promotes Christian attitudes and behavior, which makes the servers better people. 3. They have a special

¹⁹⁴ Robert J. Karris, O. F. M., "The Gospel According to Luke," in *The New Jerome Biblical Commentary*, ed. Raymond Edward Brown, Joseph A Fitzmyer, and Roland Edmund Murphy (Upper Saddle River, NJ: Prentice Hall, 1968), p. 703.; James L. D. Strong, S. T. D., *The Strongest Strong's Exhaustive Concordance of the Bible, Fully Revised and Corrected*, ed. John R. III Kohlenberg and James A. Swanson (Grand Rapids, MI: Zondervan, 2001), p. 263.; Paul J Achtemeier and Roger S Boraas, *The Harper Collins Bible Dictionary* (HarperOne, 1996), p. 320.

relationship with Jesus and the cross, which serves as an example to us all by their fortitude in living with their disability, which is their cross and uniquely connects them to Jesus' redemptive activity in the world. Their parents and family members, by association, are testaments to love and endurance. 4. Yet, if you try and your best attempts do not work, then the slippery slope of idealism says not to worry, because after all, persons with disabilities really are perpetual children, holy innocents, or an opportunity for charity. 5. Alternatively, they are a foreign being, totally other.

People influenced and acting out of the *shadow narrative* may be well intentioned, but their activity undermines persons with disabilities as individuals of interest, with dreams, hopes, gifts and desires, as well as fears and vulnerabilities. It either patronizes or magnifies the sense of *otherness* of persons with disabilities, creating a binary relationship between 'us' and 'them,' or it undermines recognition of their potential for development, as well as their needs for support to live *a human life*, as any person does: love, relationships, education, opportunities to stretch, expectations, etc. The *shadow narrative* also undermines the innate value and presence of a person simply being, without a focus on *doing* or *eliciting* particular attitudes and behaviors.¹⁹⁵

The threads of the *shadow narrative* are a subset of narratives identified within a number of different social science areas. One I found particularly interesting was a motivation-based theory of empathy purported by psychologists. It is an unconscious activity, they say, that is part of our evolutionary resilience, to feel empathy in support of ingroup preservation, and to avoid empathy for the same reason. Except in this case, empathy is avoided by identifying the outgroup as "other."¹⁹⁶ Wolfensberger, introduced in the last chapter, identified casted roles of individuals with IDD that influenced institutional settings. They share characteristics with the five threads I have named,

¹⁹⁵ Pia Matthews, "Participation and the Profoundly Disabled: "Being" Engaged—a Theological Approach," *Journal of Religion, Disability & Health* 17, no. 4 (2013): pp. 428-30, 35-36.

¹⁹⁶ Jamil Zaki, "Empathy: A Motivated Account," *Psychological bulletin* 140, no. 6 (2014): pp. 1608-1614.

though there are some slight divergences. The roles Wolfensberger named are “a menace,” “an object of pity,” “a burden of charity,” and “a holy innocent.”¹⁹⁷

In the following paragraphs I will share examples of the different threads of the *shadow narrative*. These examples come from a number of sources. Some are from ecclesial documents, some from journal articles in the developing years of ministry with persons with IDD in the US Church and other written sources, and some are from my own experiences and conversations with individuals with disabilities and their families.

1. Forever Children – Holy Innocent – Simple – Loving

The *shadow of the holy innocent, forever children* sees persons with IDD as perpetual children, regardless of their age. Insights into this understanding of individuals with intellectual disability can be discerned in the Middle Ages, when age levels for dependency and responsibility were first postulated. Infants were totally dependent on others. Although it was thought children could distinguish right from wrong and express themselves, they were excused from adult responsibilities. Adults with what is today called intellectual disability were also classified according to cognitive capacity to manage property.¹⁹⁸ Similarly dependent on others, persons with intellectual disabilities are cast with the other sentimental characteristics of children, innocent, simple and loving. In this one thread there are some slight variations that are not totally interchangeable. “Holy Innocents” most likely evolved from the historical understanding in Thomas Aquinas’ day, that persons with IDD are not able to sin, so once baptized,

¹⁹⁷ Wolfensberger, *The Origin and Nature of Our Institutional Models*, pp. 13-15.

¹⁹⁸ Parnel Wickham, “Poverty and the Emergence of Charity: Intellectual Disability in the Middle Ages (500 CE to 1799 CE),” in *The Story of Intellectual Disability: An Evolution of Meaning, Understanding, and Public Perception*, ed. Michael L. Wehmeyer (Baltimore, London, Sydney: Paul H. Brookes Publishing Co., 2013), pp. 56-57. Childhood was first delineated within the stages of infancy (until seven years old), childhood (7 to 14 years old), and adolescence (14 to 28).

they remain free of its stain.¹⁹⁹ Because it was thought that individuals with IDD would never mature and “grow up,” they are “holy innocents.” However, this belief has outlived its usefulness and it now impedes the ability for individuals with IDD to participate fully in the life of the Church and in community.

This was evidenced in the statement from Cardinal Cushing, who was mentioned in the last chapter, when he was named NAMR’s first episcopal moderator and wrote of the importance of the organization, “From the moment I became Archbishop of Boston, I resolved to do everything in my power to provide for the care and training of these best loved children of God ... these little ones as “exceptional children ...”²⁰⁰ This thread runs deep, even today, a specter in the life of adults with IDD, diminishing options for education, employment, community participation and other elements of living a fully human life referenced in Catholic Social Teaching. The new *Directory for Catechesis* promulgated by the Pontifical Council for the New Evangelization would seem to have memorialized this sentiment by its well-intentioned desire to preclude pastors from withholding Eucharist from individuals with IDD, because of concerns about their level of understanding. Very positively it says, “The sacraments are gifts from God, and the liturgy, even before being rationally understood, needs to be lived: therefore no-one can refuse the sacraments to persons with disabilities.”²⁰¹ However, it bases the statement on Pope Benedict XVI Apostolic Exhortation *Sacramentum Caritatis*, which says, “whenever possible, eucharistic communion should be made available to the mentally handicapped ... they receive the Eucharist in the faith also of the family or the community that accompanies them.”²⁰² The reference cited for the text was from the

¹⁹⁹ Thomas Aquinas, *Summa Theologica*: Translated by Fathers of the English Dominican Province, (Coyote Canyon Press, 2010). 2-2.45.5 response to obj. 3.; 2-2.15; 2-1.15.1 response to obj. 1; 2-2.15.2; 2-2.45.5, response to obj. 3

²⁰⁰ Cushing, "Letter to Fr. Matthew Pesaniello," p. 2.

²⁰¹ Pontifical Council for the Promotion of the New Evangelization, "Catechesis 2020."

²⁰² Pope Benedict XVI, "Sacramentum Caritatis," par. 178.

Synod Fathers' *Propositio* for the Synod. This particular *proposito* was for "Eucharist and the sick," and says "In particular, we ask that Eucharistic communion be guaranteed for the mentally disabled ..." and continues as above, concluding with, "It is important that those who suffer from disabilities can be recognized as full-fledged members of the Church and we have their proper place in it....".²⁰³ Again, the intent is to ensure access to the Eucharist, which is clearly demonstrating desire for participation. However, built into the access is the presumption that individuals with IDD cannot understand that Jesus is present in the host and that it is different from ordinary food. The text also casts intellectual disability as a sickness that is suffered, and thus reinforcing the connections with the threads that identify individuals with disabilities as objects of pity or have a special connection to the cross.

Another example of the pervasiveness of this thread is found in early pastoral discussions that adaptations for sacrament preparation were to be *child*-centered, rather than *person*-centered. Expectations were gauged based on if someone was *educable* or *trainable*. While these discussions at least recognized different abilities to learn, it still reflected the stereotype of perpetual childhood.²⁰⁴ Dick Dickerman, the father of a young man with IDD, spoke eloquently of the needs for individuals with disabilities to participate in process and to have demands and expectations placed on them, providing opportunities to stretch their abilities and grow. Yet, he undercut his message by his self-reference, "Father of an Exceptional Child." His son would not be a child forever, yet this father's identity belies that and reinforces otherness by his son's exceptionality.

²⁰³ Vatican News, "Synodus Episcoporum Bulletin Xi Ordinary General Assembly," (Vatican: Vatican News Service, 2005), par 44. The *Propositio* was made available to media per Pope Benedict XVI's approval, which is not standard protocol apparently. It was provided in an unofficial Italian translation which was translated into English by Google Translate.
www.vatican.va/news_services/press/sinodo/documents/bollettino_21_xi-ordinaria-2005/01_italiano/b31_01.html

²⁰⁴ Kieran, "Guidelines for the Pastoral Care of the Mentally Retarded," p. 5.

Dickerman was a pioneer member of the “Holy Innocents Guild,” a name that is still used, and continues to reinforce the image of perpetual dependency and innocence.²⁰⁵

This perception of perpetual innocence was a concern NAMR raised as an issue to be addressed numerous times, the first being in 1974. Parishes would wonder why individuals with I/DD needed access to the sacramental life of the church, “Why bother, they can’t sin anyway?”²⁰⁶ This issue still arises today. One example is Michael,²⁰⁷ a 9-year-old boy who enjoys being with his family, likes to move around, and be read to. He tends to have very noticeable tics when feeling stressed. Michael has autism. His mother worries that he is not learning anything in religious education. The parish catechetical leader however says, “Don’t worry, he’s in a perpetual state of grace.” This might sound kind, but it is also quite possible it is self-serving. After all, if Michael is in a “perpetual state of grace,” it means the parish does not have to change and learn to accompany him. Some parents might be comforted by it, but this mother was not, she felt hurt, exasperated and alone. There are admittedly real tensions in navigating this narrative. Within it is the “special needs” strand that is intertwined with all its threads. Some parents are more comfortable saying that their son or daughter has “special needs” and feel affronted by disability language. They still feel a sense of shame about disability. Pastorally, I struggle with it, but do try to accompany them and help them understand how that is restricting the possibilities they want so much for them.

Well-meaning clergy and pastoral leaders will frequently talk to parents about their “children,” regardless of age, who are innocent and provide such examples to us all of a life based in the heart, rather than the head. While it is not uncommon to refer to adults as children in relationship to their parents, when talking about individuals with IDD, it reinforces the undermining *shadow*.

²⁰⁵ Dick Dickerman, “A Parent of a Mentally Retarded Child Tells Why and How,” *ibid.*, no. 1: pp. 16-17.

²⁰⁶ NAMR Board, “Toward a National Catechetical Directory Part 1,” p. 7.

²⁰⁷ Not his real name.

I do not know if there is also a connection between the 'Holy Innocent' tradition and the "Feast of the Holy Innocents" in the Catholic Church, which remembers the massacre of children up to 2 years old by Herod in his attempt to kill the infant Jesus (MT 2: 16-18). However, it may provide a link to the thread on the special connection to Jesus and the cross.

2. Provide Opportunities for Service and "Charity"

This strand of the *shadow narrative* says that persons with disabilities helps 'us' to become better people, because we are prompted into Christian service for 'them.' 'They' have no intrinsic value as a person, but are defined by the capacity to benefit 'us.' The National Apostolate for the Mentally Retarded was established to work for, "the total integration of the mentally retarded [sic] in the full life of the Church and the life of the community as "people of God"²⁰⁸ and affirmed that individuals with IDD are integral to society and equal in dignity and value as all other persons, "They are not only recipients of what the Church offers, but they are also contributors by virtue of their individual value..."²⁰⁹ Yet, the *shadow narrative* inserted itself into the vision of the national ministry and its founding document by adding, because "... of the positive Christian attitudes they stimulate in others."²¹⁰ Cardinal Cushing, who we just discussed presents another thread of the *shadow narrative* in this one correspondence is the opportunity for service provided by individuals with disabilities, "From the moment I became Archbishop of Boston, I resolved to do everything in my power to provide for the care and training of these best loved children of God. ...*because they afford us an exceptional opportunity for service.*"²¹¹ The insidious *specter* crept into the public acknowledgement at the very beginning of organized ministry with persons with IDD in the US Catholic Church

²⁰⁸ Pesaniello, "Why?," p. 3.

²⁰⁹ "National Apostolate for the Mentally Retarded Constitution Excerpts," p. 10.

²¹⁰ Ibid.

²¹¹ Cushing, "Letter to Fr. Matthew Pesaniello," p. 2.

The call to charity is also used to explain differences in allotment of resources and talent by God when St. Basil is quoted to explain the unequal distribution of gifts by God, “If you acknowledge your possessions as coming from God, is He unjust because He apportions them unequally? Why are you rich when another is poor, unless it be that you may have the merit of a good stewardship?”²¹² He suggests that we are not really sure why this is, but it is part of God’s created scheme of things, that through sharing – others might be lifted up, and they themselves might be enriched in the process. In the fourth century, this understanding was intimately connected with monastic spirituality by St. Basil and an understanding that Christ was equally present within those who gave and those who received, and that vulnerability, need and dependency did not imply one’s value as a person. However, in the 20th century, St. Basil’s words are used to carry a different message.

“If God rewards us according to the measure of our self-giving in caring for the needs of His children, and if that reward is further enhanced when the fruits of that giving are mostly hidden, then truly among real giants of the next life will be those who have labored generously, patiently and perseveringly on behalf of His “Exceptional little ones.”²¹³

His words were used to reinforce the utility of vulnerable individuals, God’s “Exceptional little ones” to provide others the opportunity for an “exceptional” reward in the next life, by giving money or time.

The misappropriation of Christian charity, to love my neighbor as myself, is a dark and persistent shadow that continues to undermine the development of persons with IDD. Charity has lost its concern for the other and has become a patronizing force which perpetuates dependency, rather than nurturing development and growth. True charity requires sincere interest in the other person to be authentic. Unfortunately, “acts of charity” are often only *specters of charity*, which are really self-serving, self-interested or worse, disinterested. Sentimental attitudes about persons with IDD as perpetual

²¹² Fr. P.A. Duffner, O.P., “Guest Editorial: A Good Stewardship,” *ibid.* 2, no. 3 (1970).

²¹³ *Ibid.*

children further perpetuate dependency and stifle opportunities for development. There is another aspect to this *shadow*, however. Perpetual dependency can provide comfort and a sense of being needed, a sense of purpose. Sustaining this dependency then serves the perpetrator, rather than the person captured into dependency.

3. Disability and the Cross, Special Relationship with Jesus

This thread of the *shadow narrative* locates the experience of suffering within disability as a cross to bear. During the 1965 Vatican conference on disability, Pope Paul VI had a special audience with ‘the mentally deficient’ and their parents to encourage them, “You have been regarded as worthy of this cross and the Lord has given you strength to carry it.”²¹⁴ In this example, their sons’ and daughters’ with a disability is a cross, and the parents can be consoled because of their special relationship with Christ through this special connection with the cross. One can only imagine how their sons and daughters might feel when hearing that they themselves were considered a cross for their parents. Though Paul VI seemingly ignores their sons and daughters as individuals of interest, he also promised the parents God has planned for their intellectual and physical development, so they should maintain hope. It also demonstrates the duality within the *shadow narrative* that suggests light on one side with this special connection to Christ, even suggesting some shared relationship in Christ’s redemptive role, yet casts individuals with disabilities into darkness, making them invisible, undermining possibilities for their relationships.

In another conflicted example, the *US Pastoral Statement* says that persons with disabilities benefit the community through the example they provide, of the fortitude they model living with their disability.

Handicapped people bring with them a special insight into the meaning of life; for they live, more than the rest of us perhaps, in the shadow of the cross. And out of their experience they forge

²¹⁴ LoBianco, "The Spiritual Equality of All God's Children," p. 9.

virtues like courage, patience, perseverance, compassion and sensitivity that should serve as an inspiration to all Christians.²¹⁵

The bishops do not actually say that disability is the cross for the individual here, but it is certainly implied. A blunter connection with the cross is noted below, in a discussion of sacrament guidelines by the New York State Advisory Committee on Pastoral Ministry to the Handicapped below. It is unfortunately undated, but was in an NCPD archive folder on development of the national guidelines for the sacraments for persons with disabilities, so it presumably postdates the *Pastoral* and predates the initial *Guidelines* of 1995, so I estimate it is sometime within the 1980's. Regarding the Sacrament of Anointing of the Sick,

The physically and mentally handicapped bear visibly the sin of Adam (the fallen state of mankind), and the redemptive act of Jesus is more powerfully significant when administered to them. The community witnesses the fruits of Jesus' saving act applied visibly (Outward sign) to those whose very condition cries out for the new creation.²¹⁶

Disability is related to the Fall in this example, calling for the crucifixion of Christ. Rather than sharing in Jesus' redemptive action through his crucifixion, it suggests that their very condition is the symbol of its purpose, which I find very problematic. The "condition cries out for the new creation," may find its source in Augustine who said that all imperfections would be gone in the resurrection, when our bodies will be free from defect. The exception to this is if a wound is acquired through proclaiming Christ. Then it is like a medal of honor.²¹⁷ Perhaps Augustine provides the background for this passage.

In *Adam: God's Beloved*, Henri Nouwen repeatedly denies that Adam has any special or unique relationship with Christ, yet he frequently contradicts himself by the

²¹⁵ USCCB, "US Pastoral Statement," par 13.

²¹⁶ New York State Advisory Committee on Pastoral Ministry to the Handicapped, "The Sacraments," (undated).

²¹⁷ Saint Augustine, *The City of God against the Pagans*, (Cambridge: Cambridge University Press, 1998). XXII.19, L21573-21616.

way he talks of Adam and tells his story outlined within the life of Jesus' life: his hidden life, desert, public life, way, passion, death, burial and resurrection, even saying he did not claim Adam was a second Jesus.²¹⁸ This imagery is reinforced within frequent scriptural references from Jesus' life as well.

But I am convinced that Adam was chosen to witness to God's love through his brokenness. To say this is not to romanticize him or to be sentimental. Adam was, like all of us, a limited person, more limited than most, and unable to express himself in words. But he was also a whole person and a blessed man. In his weakness he became a unique instrument of God's grace. He became a revelation of Christ among us.²¹⁹

Here Nouwen sets Adam as a model for us all, based on his disability. This equates Adam's disability with his brokenness and its purpose is to provide a lesson to others, revealing Christ among us, as a special instrument of God. He says this directly in fact, "Adam did not have to practice the spiritual disciplines to become empty for God. His so-called "disability" gifted him with it."²²⁰ Nouwen suggests that Adam's vulnerability is his disability, and it is this disability of vulnerability that connects him so profoundly to Christ on the cross. But that in itself denies the vulnerability that we all share if it uniquely connects Adam to Christ. Later on Nouwen says,

Adam's ministry was unique in that he seemed unaware of all that was happening around him ... was simply present, offering himself in peace and completely self-emptied so that the fruits of his ministry were pure and abundant. I can witness that the words said of Jesus could be said of Adam: "Everyone who touched him was healed." (Mk 6:56)

... He seemed unaware of all that was happening around and through him yet, by his eyes and by his presence, said to us, "Don't be afraid."²²¹

²¹⁸ Henri JM Nouwen, *Adam: God's Beloved*, (Maryknoll, NY: Orbis Books, 2012). electronic book. p. 30.

²¹⁹ Ibid.

²²⁰ Ibid.

²²¹ Ibid., p. 64.

I know that I couldn't have told Adam's story if I hadn't first known Jesus' story. Jesus' story gave me eyes to see and ears to hear the story of Adam's life and death.²²²

These are just a few examples of Nouwen's relating Adam to Christ, yet denying a special connection. The prevalence of his denials reinforces the concern, rather than diminishes it.

It is not only in decades old text that I have encountered this thread of the *shadow narrative* that connects disability with the cross in some misconstrued participation in Christ's redemptive activity. A priest once thought he was consoling a mother whose daughter had just died. She was a young woman with intellectual disability who had a long bout with medical issues as well. The priest told this grieving mother that she could be consoled knowing her daughter's disability somehow contributed to the healing of the world through a special connection with Christ's crucifixion. This mother did not feel consoled. In fact, she saw very little need for a church that would proclaim such a God. There is no reconciling this statement with anything proclaimed in Catholic Social Teaching or the *Pastoral*. It is a twisted relationship to the cross.

Support for this understanding of the *shadow narrative* is present within some of the Church's recent social documents and papal statements. While Pope John Paul II fully affirms the full human dignity of individuals with disabilities in his texts, the *shadow narrative* of the cross dilutes his message. In *Laborum Exercens (Through Work)*, (1981) disability is associated with those who are weak and sick and the cross is insinuated, "in spite of the limitations and sufferings affecting their bodies and faculties, they point up more clearly the dignity and greatness of man."²²³ Addressing individuals with disabilities in his homily for the Jubilee of the Disabled in 2000, John Paul says "every person marked by a physical or mental difficulty lives a sort of existential 'advent', waiting for a 'redemption' that will be fully manifest, for him as for everyone, only at the

²²² Ibid., p. 126.

²²³ Pope John Paul II, "Laborem Exercens (through Work), Encyclical for 90th Anniversary of Rerum Novarum " (Vatican: Libreria Editrice Vaticana, 1981), par 22.

end of time. ... By your presence, dear brothers and sisters, you reaffirm that disability is not only a need, but also and above all a stimulus and a plea ... a request for help."²²⁴ These cast individuals with disabilities either as models of valor for how they live with their suffering, or opportunities for service rather than people who need human authentic human relationships. Which, again, does not deny he also affirms them as subjects.

Four years later, his characterization seems more conflicted when addressing attendees of the International Symposium on the Dignity and Rights of the Mentally Disabled Person (2004). Disability is a sign of their 'wounded humanity' and they are "living icons of the crucified Son. They reveal the mysterious beauty of the One who emptied himself for our sake and made himself obedient unto death" and they are "humanity's privileged witnesses."²²⁵ John Paul does again affirm full human dignity of individuals with disabilities and their need for appropriate supports to participate and develop as they are able to, rather than as others do and he speaks to their need for love and intimacy.²²⁶ In fact I was surprised by his explicit references to their emotional and sexual needs, which is clearly at odds with the 'perpetual child' thread of the *shadow narrative*. Yet, these points do not seem to impress people as much as imagining connections to the suffering Christ.

This thread of the *shadow narrative* locates the experience of suffering within disability as a cross to bear, without considering the role of attitudes, rejection and marginalization in the experience. I am not referring to the social model of disability

²²⁴ "Homily, Jubilee of the Disabled," (Vatican: Libreria Editrice Vaticana, 2000), par 2, 5.

²²⁵ "Message of John Paul II on the Occasion of the International Symposium on the Dignity and Rights of the Mentally Disabled Person," (Vatican Libreria Editrice Vaticana, 2004), par 2, 6. Investigating his language development in discussions about suffering and disability juxtaposed with his own progressive experience with Parkinson's Disease might yield interesting considerations.

²²⁶ Ibid., par 5.

here, which I find incomplete.²²⁷ My concern is theological. Because individuals with IDD are considered to be incapable of sin, both by this thread and the 'Holy Innocent' thread, they are innocent as Christ was innocent, and so their disability is connected with the redemptive act of Christ' crucifixion. However, this disavows the Church's belief that Christ's sacrifice is a unique, unrepeatable event.²²⁸

But there is more to consider here. It implies that there is a problem with disability, that it mars creation, rather than recognizing disability is part of ordinary experience of being human. Perhaps we can discern its roots in Augustine. Although maintaining that each person's difference is part of their beauty, all uniqueness has a purpose, he notes imperfections as well. Brian Brock notes that Augustine suggests such individuals may be "divine acts of communication" which could reveal God's glory (Jn 9:3).²²⁹ Valuable though Augustine's many contributions are, it is time to update these particular insights based on the *growing end of human dignity* proclaimed at Vatican II. Even without considering the changes in ability that happen through the

²²⁷ The social model considers disability to be socially constructed by the attitudinal and constructed environmental barriers. The impact of these are very real spawned by the cult of normalcy, which I will discuss further shortly. However, it inadequately accounts for the very real experience of living with particular disabilities, both that someone is born with or develops during their life. Again, for further discussion of models, see: Johnstone, *An Introduction to Disability Studies, Second Edition*. pp. 22-27, 106-106; World Health Organization, "Towards a Common Language for Functioning, Disability and Health: ICF. Geneva, Switzerland: World Health Organization."; World Health Organization and The World Bank, "World Report on Disability."; Goodley, *Disability Studies: An Interdisciplinary Introduction*. pp. 1-26; Shakespeare, *Disability Rights and Wrongs Revisited*. pp. 1-69. The first three resources provide good introductions to the different models of disability. The last two resources provide a more nuanced exploration of the different issues associated with naming any one lens about disability.

²²⁸ Catholic Church, CCC, 613-618.

²²⁹ Brian Brock, "Augustine's Hierarchies of Human Wholeness and Their Healing," in *Disability in the Christian Tradition: A Reader*, ed. Brian Brock and John Swinton (Grand Rapids, MI; Cambridge, U.K.: William B. Eerdmans Publishing Company, 2012), pp. 72-76; Saint Augustine, *The City of God against the Pagans*. XXI.8, L19975-20051.

lifespan, many individuals with disabilities adamantly claim their disability as part of their identity, they would not be themselves without it. Although David Atkinson, who we met in chapter one, says he wants to be considered a person first, he also says he would not recognize himself without cerebral palsy.²³⁰ That God's glory could be made visible through the lives of individuals with disabilities is not doubted. But rather than presenting them as a particular type of prophet, as "people of the heart," I would suggest that the glory of God is revealed in the life of a flourishing human being, which is the possibility for everyone.

4. *The Slippery Slope of Idealism*

The fourth strand of the *shadow narrative* is that of idealism that mutes the call of the Gospel by what is *possible*. In the *Pastoral*, as well as the four documents on sacraments and catechesis, individuals with disabilities are to be included in ordinary evangelization and catechetical programs as much as *possible*.²³¹ Even though the *Revised Guidelines* give much stronger direction than the original ones, persons with disabilities are to be:

integrated into the ordinary programs. They should not be segregated for specialized catechesis unless their disabilities make it *impossible* for them not to participate in the basic catechetical program. Even in those cases, participation in parish life is encouraged in all ways *possible* (*emphasis added*).²³²

And later, its concluding paragraph notes the communal identity of the body of Christ,

"are presented to all who are involved in liturgical, pastoral, and catechetical ministry. All persons with disabilities have gifts to contribute to the whole Church. When persons with disabilities are embraced and welcomed, and

²³⁰ Conversation on language at peer-support group for mothers of individuals with disabilities at St. John the Evangelist Church, Bergenfield NJ, 2012.

²³¹ USCCB, "US Pastoral Statement," par 25; "Revised Guidelines," par 5; "Guidelines for Celebration of the Sacraments with Persons with Disabilities," (Washington, D.C.: U.S. Catholic Conference, 1995), par 5.

²³² "Revised Guidelines," par 5.

invited to participate fully in all aspects of parish community life, the Body of Christ is more complete.”²³³

However, the case for respectful and meaningful participation is not helped by referring to the *NDC* in closing with the following statement, “The Church owes persons with disabilities her *best efforts* in order to ensure that they are able to hear the Gospel of Christ, receive the sacraments, and grow in their faith in the fullest and richest manner possible.”²³⁴ *Best efforts* is overly vague. Perhaps the bishops had some criteria in mind when they said this. But with the realities of congregational life, it is problematic.

While the Church is well-intentioned, the focus is on making room, expanding the space so that persons with IDD can fit in. However, the focus is essentially on “fixing” them. What often happens with *best efforts* is that pastoral ministers *try their best*, but it does not work, regardless of whether or not the attempt was well informed. The slippery slope of idealism offers pastoral ministers an option to abrogate their responsibility to ensure that persons with IDD are “embraced, welcomed and invited” to participate fully in all aspects of parish community life.”²³⁵ It is a more elusive shadow narrative, because it appears to reach for integrated inclusion and full meaningful participation, yet it tells us to settle on possibility. The dilemma with this statement is the ambiguity of what constitutes “impossible” for someone to participate. A parish can *try* to include someone in the parish catechetical program. It can *try* to support someone to participate in parish life. But if it does not “work,” they say, “they *tried*, but it is not possible.” They may not have had effective guidance when setting up the pastoral plan, but once energy has been expended, it can be hard to motivate people again, unless they have the heart to do so.

Interestingly enough, the Catholic Church does not promote this exemption in conversations on abortion. However, it realizes that abortions happen, and that healing is required, so there are retreats and other pastoral practices established for this very

²³³ Ibid. Conclusion.

²³⁴ Ibid.

²³⁵ Ibid.

purpose. Yet, for persons with disabilities, there is the hint that it is okay to just do the best as possible, keeping meaningful participation in a fully embodied way always out of reach and essentially reinforcing the first three threads of the *shadow narrative*. This implies that it really does believe individuals with IDD are perpetual children, who cannot develop any further, even with supports and expectations of flourishing; that they really cannot sin, so do not really need access to ongoing sanctification through the sacraments; that the body of Christ really is no different, with or without them. There is the implication that the Church really does not understand why some people have such conditions and *they are so different*. The *pall* underlying idealization is the insinuation that it does not really matter after all, because one or all of the first three *shadow narratives* is operative. There is the belief that God will take care of ‘them’ after all, so there is no need not worry.

5. Otherness

The fifth strand of the *shadow narrative* sees persons with disabilities as very different, ‘other.’ All of the threads of the *shadow narrative* set up persons with disabilities as “other,” and this is the most blatantly negative, so it could make sense to introduce first. I saved it for the last for two reasons. The other narratives are far more prevalent, though I do encounter this one, and the others, though marginalizing, on a conscious level could at least be considered well-intentioned.

One of the suggested edits to the *Pastoral* sought to strengthen the responsibility of the Church to accompany families living with disability. Bishop Evans rightly noted the difficult reality that many families live with, due to insufficient support from society and the Church. However, the US Bishops rejected it because of its extreme negativity expressed in the suggestion, which they said could not be applied to all families living with disability. In the language of the day, Bishop Evans said,

... The crisis affecting families with a defective member is compounded because of the presence of that disabled offspring. ... They have been deeply hurt and desperately need healing of mind and spirit. They have a special,

lifelong burden and for that reason need the sustaining influence of the Church...²³⁶

This quote emphasizes the impact of the individual's disability on the rest of the family with no mention of individual value of the person. The individual with a disability does not seem to have human status, they are simply a *defective member* or *disabled offspring!* It is another example of the gloomy cast that diminishes the humanity of the individuals with a disability by referring to them as defective and a burden. Although it was not incorporated into the *Pastoral*, I include it because this view still persists.

Anthony is a teenager who enjoys gardening, watching movies, whether at home or at the theater with his parents and working on skills for independence. A real treat for him is to have popcorn at the movies. Anthony also has autism. He attends Mass with his parents every week, but like any teenager, he is prone to moments of rebellion. This happened one Sunday during Mass, so his mother took him to the Gathering Space to help him work through it. When she explained this to the concerned usher, he said, "my son has two of them, they're animals." While the above quote never said this in his discussion about families' burdens, it may not be very far to go from "defective member" to not really human, to animal. While some parents may need help realizing their son or daughter is more capable than they realize, they still value them as gifts of life from God and seek to do their best for them in a world of typically limited options.

B. Shadow Narrative Marginalizes People

The *shadow narrative* allows those without disabilities to distance themselves from its subjects. It has existed long before the beginning of ministry with persons with disabilities, establishing boundaries for participation and nonparticipation within communities, eclipsing the light of the Gospel. To clarify an important point, the preposition 'with' is contemporary language, 'for' was the preposition of the 1960's. However, any marginalization precludes the possibility of the preposition 'with' to be valid.

²³⁶ NCCB, "Proposed Action Item Amendment: Pastoral Statement on Handicapped People." Rejection no. 16 from Bishop George Evans.

Community identity and culture are based on a mixture of shared and valued characteristics, including physical ones such as skin color, body types, facial features, and attributes associated with abilities, attitudes, social practices, etc. Within community identity there is a sense of connectedness, which has historically laid the foundation for development in human society to guide resource sharing and protective practices. A part of tribalism supports internal group cohesion by defining who is an outsider. This would be important in early human community development, the ability to feel empathy for one's offspring, clan, and others in one's group, as well as to not feel empathy for outsiders. The evolutionary value of such identification is suggested by the biological indicators in brain scans during empathic activities, which occurs unconsciously, and has responded over time to changing needs of the group based on shifting dynamics of society. Jamil Zaki, a psychologist who researches this, identifies three forms of empathy: sharing or emotional empathy, thinking, theory of mind or cognitive empathy, and caring about, compassion or motivational empathy. Motivational empathy moves people to action, "to improve someone else's well-being."²³⁷ This particular form of empathy, compassion or motivational empathy, will be important in my constructive proposal and discussion of interpersonal identification.

The *shadow narrative* focuses attention on persons with disabilities, therefore marginalizing *them* by what Thomas Reynolds names the "cult of normalcy." The cult of normalcy explains the process of marginalization that occurs within societies, informed by its particular cultural preferences. Reynolds charges that the cult's "insidious undertow" is responsible for developing a caste system that determines normality and abnormality for the community. This caste system then decides who is normal and who is abnormal, based on the extent someone shares characteristics with either group.²³⁸ The *shadow narrative functions as the undertow* that Reynolds identifies. It is a stream

²³⁷ Zaki, "Empathy," pp. 1608-1611.; The War for Kindness: Building Empathy in a Fractured World, (New York: Crown, 2019). pp. 5-7, 178-180, Appendix A.

²³⁸ Reynolds, *Vulnerable Communion: A Theology of Disability and Hospitality*. L704-L718.

of representations of disability that is influenced by a meaning that is hidden on the surface. Just as the undertow, it is harmful, even deadly.

Society provides a framework for knowing what is good, establishing standards for development and behavior. Human identity develops through relationships and participation within this communal framework, and is influenced by the quality of relationships formed, as well as the degree of acceptance that is felt. The economy of society, what provides access to the goods of it, is based on the established framework within the cult of normalcy, which prioritizes such characteristics as independence, intellect, and strength. A person's "body-capital" reflects their synergy with these socially desirable characteristics. The stronger and more capable someone is, the more "body-capital" they will have. Concurrently, the less synergy someone has with what is desirable, the less body-capital they have, and thus, the less visible they are within society.²³⁹

Sameness is consistent and comfortable, while difference is inconsistent and uncomfortable. Difference, therefore, causes fear, which engenders concerns for power and security. The cult of normalcy establishes protocols and boundaries to enhance comfort and safety, which society reinforces through unspoken consensus. Those without body capital have no currency to participate, and thus are rendered invisible. Prejudices and stereotypes denigrate those who are considered abnormal through stigma and taboo.²⁴⁰ The US Bishops acknowledged the cult of normalcy in the *US Pastoral Statement*, though not by name, when they said, "we tend too often to think of 'them' as different and therefore "not quite one of "us."²⁴¹ Bishop Wycislo would agree with Reynolds' assessment of the undertow feeding this darkness. He wanted to strengthen the language of the text to say, " Oftentimes it is our own insecurity, fear or inability or discomfort in communicating with them." The bishops thought that the text

²³⁹ Ibid., L734, 798-913.

²⁴⁰ Ibid., L902-L955.

²⁴¹ USCCB, "US Pastoral Statement," par 2.

carried the point sufficiently.²⁴² Though it does make the point, it does not shine the light of inspection sufficiently onto “us” to identify the sources for this prejudice, and allows attention to remain focused on how *they* can change to fit into *our* space.

Stigma is appointed to the “spoiled body,” because of differences that are based on physical, moral, behavioral, cultural, religious, gender, or ability characteristics. The person becomes equated with whatever their stigma is, such as disability. For example, someone with Down Syndrome could be referred to as “the Down’s child.” Marginalized groups are either invisible to dominant groups or visibly excluded, because they lack the currency to participate.²⁴³

Two examples unrelated to disability in my own life illustrate stigma. During the 1980’s and early 1990’s, I was a field sales engineer in the high-tech field, selling semiconductors. When interviewing for a position, it seemed that everyone, but the janitor had interviewed me, yet I still was not offered the position. I was engaged at the time, so I thought my engagement ring might have raised questions in the hiring manager’s mind, wondering when I would get pregnant, as that was a common excuse to not hire women at the time. I raised the subject somewhat jokingly. After I was hired, he told me that the model of the perfect salesperson in his mind was Dan. He had unconsciously included Dan’s gender in his perfect profile, because at the time there were few counter examples. Years later, I became pregnant while working for another company in the same industry. They had to rewrite the commission policy because of my situation. Going on maternity leave four weeks before my son was born had me leaving in the middle of the month, and at the time the policy stipulated that anyone who left before the end of the month would lose all commissions. It obviously was written without foreseeing pregnancy as the reason to leave. The expectation was that anyone who left was leaving to go to a competitor. Women, or at least women’s experiences,

²⁴² NCCB, “Proposed Action Item Amendment: Pastoral Statement on Handicapped People.” Proposed by Bishop Wycislo. Rejection #4.

²⁴³ Reynolds, *Vulnerable Communion: A Theology of Disability and Hospitality*. L963-L988.

were not a part of the framework for writing policy and procedures in a male-dominated industry.

These examples illustrate the impact of hidden assumptions and generalizations within the *cult of normalcy*. Fortunately, both situations worked out for me. However, individuals with disabilities and other marginalized groups typically are not as fortunate. Despite biases against women in the workforce at the time, I still had the advantages of race, education, and status. I was also recommended by another employee. While gender made me invisible, relationships, education and race increased access.

Taboos challenge essential values and need to be avoided because they are contrary to what is considered natural. Words note deviancy from what is natural and normal that corrupt ideals embedded in social conventions. References such as “[c]rippled, maimed, diseased, bastard, impotent, idiot, imbecile, retarded, etc., are used to isolate such persons from community life.”²⁴⁴ Lacking independence, in the *cult of normalcy*, persons with disabilities can be viewed as a burden at best, and at worse, the result of sin or a lack of faith, or totally other. Disability is seen as the opposite of God’s created order, which is good, and therefore presents a challenge to the Church. “The good of the community, then, requires that disability be ritualized into normalcy or rendered invisible if the community’s sense of orientation and meaning has been threatened with fragmentation and chaos. Disorder is impure. Human beings fear lack of order, which symbolizes falling apart and disorientation.”²⁴⁵ Somehow, this disorder in the community needs to be explained, so it can be understood and managed.

Research into motivational theory of empathy can help with this. It has identified a range of responses people are likely to give when anticipating situations expected to cause empathic feelings. The outcomes are based on their assessment of the situation. Faced with contradictions to God’s created order as Reynolds describes, vulnerable individuals can be become falsely perceived merely as “gifts” to those who have more

²⁴⁴ Ibid., L996-L1026.

²⁴⁵ Ibid., L1039.

resources to become Christ-like. This resolves the conflict of how a benevolent God could allow such “deviancy” into the world, while also maintaining established patterns of status and power. Remember how Duffner motivated people to give time or money to NAMR, by referring to St. Basil.²⁴⁶ It is reasonable to see how *shadow charity* could develop from this mindset.

Another narrative, like the fifth strand of the *shadow narrative* says that the individuals or group do not feel or experience emotions in the same way as the observer(s) do. In other words, they are something less than fully human. There is no sense of identification with the person in this example. Recalling the exchange above between Anthony’s mother and the usher, “My son has two of them, they’re animals!” His choice of words denies his relationship of grandfather to them. Wolfensberger attributed such blanket hostility to fear of one’s “own weaknesses and their own humanness.”²⁴⁷ This perspective can also reinforce belief in a just world, by deciding that they deserve whatever the situation is, and therefore feel justified to ignore them.²⁴⁸ This added dimension of “othering,” that it is deserved, is not part of the *shadow narrative* I discovered operative within the US Catholic Church. Regardless, this practice of “othering” is certainly present in society. President Trump regularly uses language that dehumanizes immigrants, such as “thugs” and “animals” and stokes fear about America losing its identity to “immigrant invasion.”²⁴⁹

²⁴⁶ Duffner, "Guest Editorial: A Good Stewardship," p. 2.

²⁴⁷ Wolf Wolfensberger, "Our Moral Responsibilities as Providers or Utilizers of Human Services," *The Bulletin (Publication of the Christian Association for Psychological Studies)* (1980): Author’s manuscript copy obtained with gratitude from Robert J. Flynn, p 4 of 10.

²⁴⁸ Zaki, "Empathy," pp. 1613-1614.

²⁴⁹ Philip Rucker, "'How Do You Stop These People?': Trump’s Anti-Immigrant Rhetoric Looms over El Paso Massacre," *Washington Post*, August 4, 2019 5:04 p.m. 2019; Ben Zimmer, "Where Does Trump’s ‘Invasion’ Rhetoric Come From?," *The Atlantic*, August 6 2019.

The hierarchical dualism operative in the *cult of normalcy* is also found in Elizabeth Johnson's discussion of the kingship model that underpins Christian theology. Noting its source in western culture, Johnson points to the patriarchal values that inform human society, its relationship with the earth and God, resulting in a framework of hierarchical dualism. The "kingship model" views the world within dualistic categories; one half of a pair is subordinated for the use and benefit of the other half, with little or no intrinsic value of its own.²⁵⁰ In such a model, humanity is detached from and more important than nature; man is separate from and more valuable than woman; God is disconnected from the world, utterly and simply transcendent over it, as well as more significant than it. Johnson names the kingship model to argue the connection between the plight of women and of the earth at the hand of hierarchical dualism. Strength, masculinity, independence, wealth, and ability dominate over vulnerability, dependence, femininity, poverty, and disability. The instrumental nature assumed within the kingship model further develops the cult of normalcy's connection to the *shadow narrative*, particularly in the *shadow charity* and *shadow cross* threads.

C. Marginalization Creates A Space Called 'On the Margins' (OTM)

The marginalization which results from the *shadow narrative* is a significant player in creating the restricted space popularly called, "on the margins" (OTM). I discuss OTM as *if* it is a specific geographical location. It has become very popular in Catholic pastoral discussions to talk about finding Christ "on the margins." A quick Google search on "Pope Francis, 'on the margins'" yielded about 336,000 results in 0.57 seconds, and the same search for USCCB found about 24,200 results in .36

²⁵⁰ Elizabeth A Johnson, *Women, Earth, and Creator Spirit*, ed. Notre Dame Saint Mary's College, vol. 1993 (Mahway, NJ,: Paulist Press, 1993), pp. 3-22. While her argument has a narrow focus in this essay, it works well for the current conversation, expanding its scope to human society and other marginalized groups.

seconds.²⁵¹ I only want to point out the widespread use of it, and caution the potential for it to become subsumed into the sentimental threads of the *shadow narrative*. Yes, Christians believe that Christ is found within every person, and that Christ is served in serving this person. However, there's real risk again of the person being rendered invisible within the "face of Christ."

In reality, however, it is a location of attitude, there is no city, town, county, state or country named, OTM. It cannot be found on any map, though the spaces considered "on the margins" are obvious within any community. They are physically the spaces considered less desirable for many reasons. Attitudinally, they are revealed by who is absent in the general life of a community, yet is not missed.²⁵² While the *seemingly* positive threads which attribute an exalted status with God, such as holy innocent or an opportunity for "charity," the implication is still that *they* are not like *us*,²⁵³ and restricts their contributions to a predefined space based on their disability, to be used by others, regardless of their own ideas and interests. The devaluation and isolation felt by the citizens of OTM is the same whether regarded with positive or negative labels. God did not create this space named OTM. Humanly designed social structures create it by deciding what qualities are valued by the community and therefore which people are valued.

²⁵¹ Google Search, "Pope Francis, 'on the Margins'," Google https://www.google.com/search?q=pope+francis%2C+%22on+the+margins%22&rlz=1C5CHFA_enUS747US747&oq=pope+francis%2C+%22on+the+margins%22&aqs=chrome..69i57.6682j0j7&sourceid=chrome&ie=UTF-8; ; "USCCB, 'on the Margins'," Google https://www.google.com/search?q=USCCB%2C+%22on+the+margins%22&rlz=1C5CHFA_enUS747US747&oq=USCCB%2C+%22on+the+margins%22&aqs=chrome..69i57.6908j0j8&sourceid=chrome&ie=UTF-8.

²⁵² John Swinton, "From Inclusion to Belonging: A Practical Theology of Community, Disability and Humanness," *Journal of Religion, Disability & Health* 16, no. 2 (2012): pp. 183-184; Erik W Carter, Elizabeth E Biggs, and Thomas L Boehm, "Being Present Versus Having a Presence: Dimensions of Belonging for Young People with Disabilities and Their Families," *Christian Education Journal* 13, no. 1 (2016): pp. 131-146; USCCB, "Economic Justice for All: Catholic Social Teaching and the U.S. Economy," par 77-80.

²⁵³ "US Pastoral Statement," par 2.

Human beings collectively create OTM and individually perpetuate it, actively by acceptance, or passively through lack of resistance. It is populated by groups of individuals the society at large does not appreciate and has decided are expendable.²⁵⁴ In fact, individuals with IDD are significantly more at risk of violence against them. Children and teens with IDD are four times as likely to be bullied and teens and adults with IDD are four times as likely to be victims of violence against their person.²⁵⁵ A prenatal diagnosis that indicates the possibility of a disability leads to abortion 80% of the time if they are not told of opportunities for perinatal hospice, and is usually the preferred advise of their doctors.²⁵⁶ The *cult of normalcy* decides what characteristics are valued and devalued, and hence, *who* is valued and devalued.

Besides the isolation and violence noted above, there are two concerns with this. Operating from within the cult of normalcy, persons with disabilities and the community as a whole, miss opportunities to interact and connect, learn from each other, and develop new awareness of what each other is capable of. Also, OTM can be sentimentalized as a special place to encounter Christ. It is someplace to visit and be inspired, either by the simplicity of the inhabitants of OTM, by opportunities for service to them, or by their special connection with Christ. Although soundly contradicted by essential principles of Catholic Social Teaching, it continues to persist, such is the

²⁵⁴ Pope Francis, "Looking for Mercy - Bull of Indiction of the Extraordinary Jubilee of Mercy," (Vatican: Liberia Editrice Vaticana, 2015), par 15; "Evangelii Gaudium (Joy of the Gospel)," (Vatican City: Liberia Editrice Vaticana, 2013), par 67, 99-100.

²⁵⁵ Jamilia J Blake et al., "National Prevalence Rates of Bully Victimization among Students with Disabilities in the United States," *School Psychology Quarterly* 27, no. 4 (2012); Joan R Petersilia, "Crime Victims with Developmental Disabilities: A Review Essay," *Criminal Justice and Behavior* 28, no. 6 (2001): pp. 655-694.

²⁵⁶ Michelle D Almeida et al., "Perinatal Hospice: Family-Centered Care of the Fetus with a Lethal Condition," *Journal of American physicians and surgeons* 11, no. 2 (2006); Tracy Winsor, "Prenatal Diagnosis and Considerations for Parent Advocacy around Prenatal Screening and Diagnostic Testing," in *A presentation for Social Workers* (location unknown: Be Not Afraid, 2017). Received from author.

enduring power of the *shadow narrative*, because it is a product of the *cult of normalcy*, its collective narrator.

I have already acknowledged that other groups are also marginalized by the cult of normalcy, though this discussion is specifically focused on persons with IDD. It must also be noted, however, that persons with IDD have been persistently marginalized while other groups advance. Other marginalized groups have an easier time speaking up for themselves, drowning out the voices of persons with IDD. Underlying this, however, as has already been said, is the *shadow narrative* thread of idealism which says, "It really does not matter, because God does, after all, have them covered. Therefore, the Church does not need to be concerned." These are the five threads of the *shadow narrative*, including examples and implications for persons with IDD within the life of the Church, and its influence on the process of marginalization. Next, I will introduce a well-known example that has had far reaching implications.

D. Henri Nouwen and the Shadow Narrative: The Sphere of Sentimentalism

Adam: God's Beloved by Nouwen is a well-known story that has raised attention and interest in persons with disabilities who had been mostly invisible within faith communities and society. Three threads of the shadow are interwoven within Nouwen's account of his life at Daybreak and his relationship with Adam, but the overarching focus and interest is typically oriented toward a simplistic and/or sentimental perception of persons with IDD. Nouwen was impacted profoundly by his relationship with Adam, "who more than any book or professor led me to the person of Jesus."²⁵⁷ It would seem that living with Adam brought meaning and life to Nouwen's understanding of Christian theology. Perhaps it could be said that before Adam, Nouwen's faith was more intellectual and through Adam it took flesh and became incarnational.

However, elements of the *shadow narrative* permeate Nouwen's telling of Adam's story through the numerous sentimental accountings of Adam's simplicity,

²⁵⁷ Nouwen, *Adam: God's Beloved*. p. 16.

patience, and love serving as Nouwen's spiritual guide. In these moments Nouwen gives words to Adam's intentions, yet in so doing, Adam seems to recede, obscured by Nouwen's projections. "Adam was communicating with me, ... reminding me that he wanted and needed me to be with him unhurriedly and gently. He was clearly asking me if I was willing to follow his rhythm and adapt my ways to his needs."²⁵⁸ Yes, Adam needed Henry to move slowly, otherwise, his brusqueness set off a seizure. However, his seizure was a consequence of Nouwen's actions, not Adam reminding or asking for anything. He is projecting agency and intention here. In other accounts, Nouwen shares his evolving perceptions of Adam and his growing need for Adam,

Eventually I found myself confiding my secrets to him, telling him about my moods, my frustrations, my easy and hard relationships, and my prayer life. What was so amazing about all this was the very gradual realization that Adam was really there for me, listening with his whole being and offering me a safe space to be. I wasn't expecting that, and though I do not express it well, it really happened.²⁵⁹

... My closeness to him and to his body was bringing me closer to myself and to my own body. It was as if Adam kept pulling me back to earth, to the ground of being, to the source of life. My many words, spoken or written, always tempted me to go up into lofty ideas and perspectives without keeping in touch with the dailiness and beauty of ordinary life. Adam didn't allow this. It was as if he said to me, 'Not only do you *have* a body like I do, Henri, but you *are* your body. Don't let your words become separated from your flesh. Your words must become and remain flesh.' Adam was relating to me, was becoming central in my life. I started to experience a true relationship with and love for Adam."

Adam was no longer a stranger to me. He was becoming a friend and a trustworthy companion, explaining to me by his very presence what I should have known all along: that what I most desire in life – love, friendship, community, and a deep sense of belonging – I was finding with him. His very

²⁵⁸ Ibid., p. 47.

²⁵⁹ Ibid.

gentle being was communicating with me in our moments together, and he began to educate me about love in a profoundly deep way. ..²⁶⁰

Henri acknowledged a growing reliance on Adam in these passages, his sense of Adam as a peaceful presence at the center of his life, and a trusted friend and teacher whose presence was a stabilizing force on his inner senses of turmoil just by thinking of Adam, who was “walking with me in my confusion through the wilderness of *my* life.”²⁶¹ While claiming distinct thoughts and intentions by Adam, Nouwen contradicts himself when he then claims Adam had no ability for reflective thought on love, and seemed unaware of what happened around him.²⁶² It is common in vernacular language to note someone taught a lesson without awareness of having done so. The concern here is that individuals with IDD are often treated as blank slates to project intentionality onto. For this reason, it is preferable to own one’s perception and speak of what is learned.

Because of the transformative potential of being in relationship with someone who is so dependent, it is reasonable to reflect on it within a theological framework, particularly for a theologian. Living in such close proximity with Adam is bound to change Nouwen, spending two hours daily taking care of his physical needs that included bathing, shaving, brushing his teeth, dressing him and feeding him. “Living close to Adam and the others brought me closer to my own vulnerabilities. While at first it seemed quite obvious who was handicapped and who was not, living together day in and day out made the boundaries less clear.”²⁶³ Vanier told Nouwen, “L’Arche is not built around the word but around the body. We are so privileged to be entrusted with the

²⁶⁰ Ibid., pp.48-49.

²⁶¹ Ibid.

²⁶² Ibid., pp. 49, 64.

²⁶³ Ibid., p. 77.

body of another.”²⁶⁴ This is an eloquent way of saying that the Word is embodied action, not intellectual concepts, and it forced Nouwen to reevaluate all the assumptions of his life.

I do not doubt the intensity of Nouwen’s feelings and experiences through being with Adam and taking care of him. However, Nouwen’s frequent projections of his inner perceptions onto Adam are problematic because they overshadow him. It is as if Adam became hidden and made into an icon of sorts, becoming less of a person. Nouwen’s experiences at Daybreak in general, and with Adam in particular, were completely different from anything he had experienced before. For much of his adult life Nouwen was steeped in academia reflecting on deep theological mysteries. But he was never held accountable for the mundane realities of life, such as laundry and washing dishes, and was considered an absent-minded professor of sorts.²⁶⁵

Nouwen was totally unprepared for the experience of profound physical closeness with another human being, who was also totally dependent on him. Adam’s total dependency brought Nouwen into contemplation on the Incarnation in a way that his books never had. He now wondered about the nature of community, life and love. “Adam was so fully alive to me, and he shed light on all these questions. ... From my heart I could offer him some care that he really needed, and from his heart he blessed me with a pure and lasting gift of himself.”²⁶⁶ Nouwen’s meaning is unclear, but it sounds like his own desires are reflected in this statement and seems to reveal a need to receive something for his care to have meaning. “Caring for Adam was allowing Adam to care for us as we cared for him. Only then did Adam and his assistants grow in mutuality and fruitfulness. Only then was our care for Adam not burdensome, but

²⁶⁴ Ibid., p. 46. This quote perhaps take on new meaning in light of the revelations earlier this year about Vanier’s abusive relationships with some L’Arche assistants. However, I will leave my comments as they are without further speculation.

²⁶⁵ Michael Ford, *Wounded Prophet: A Portrait of Henri J. M. Nouwen*, (New York: Doubleday, 2001). L 2681.

²⁶⁶ Nouwen, *Adam: God's Beloved*. pp. 51-52.

privileged because Adam's care for us bore fruit in our lives."²⁶⁷ While it acknowledges the need for respect in such a relationship that includes mutuality, true charity is supposed to be disinterested relative to outcome, focused on the other, without concern for our needs and preferences or bearing fruit. It is subtle, but it as if Nouwen needs to project mutuality in care to assuage his spiritual hunger, and in the process 'using' Adam as an instrument.

The intensity of Nouwen's emotions are understandable. I experienced the profound sense of awe and wonder when in close relationship with and for someone who is totally dependent on me when I became a mother. Yet what I learned during the stages of complete dependency was not what my son was teaching me, but rather what I was learning about myself through my responses to the experience of his abject vulnerability and dependence on me.²⁶⁸ It included moments of awe and connectedness I experienced caring for this person's every bodily need, at times amazed at how other-centered I could be for my son. Yet I also felt shame at the selfishness that I had to face in myself as well.

Nouwen experienced the pain that can come from such close interactions with someone so vulnerable. He experienced a severe internal crisis brought on by his close proximity with Adam and the others,

brought me closer to my own vulnerabilities. ... weakening many of the defenses I had created around my inner handicaps. ... Toward the end of 1987 I realized I was heading for a crisis. I wasn't sleeping well and I was preoccupied by a friendship that had seemed life-giving but had gradually become suffocating for Me ... I found myself overwhelmed by intense feelings of abandonment, rejection, neediness, dependence, despair. Here I was in

²⁶⁷ Ibid., p. 59.

²⁶⁸ Jürgen Moltmann, *The Spirit of Life: A Universal Affirmation* (Fortress Press, 1992; repr., Century Religious Thought: Volume I, Christianity), 66. Reading this recently was a nice affirmation of my own interpretation of the experience.

the most peaceful house, with the most peaceful people, but raging inside myself.”²⁶⁹

Encountering someone who is truly dependent on us can bring out unexpected feelings, such as feeling caged in, anxious, anger, awe, love, and more. If we allow ourselves to be changed by the encounter, letting down barriers and masks, we may not be so vulnerable with every person we meet, but we are more aware of our weaknesses and potentially also more accepting of our need for others, which could then open up wounds that had been only scabbed over, not fully healed. Nouwen’s narration of Adam’s story seems to be more the story of Nouwen’s journey of discovery through and with Adam, encountering his frailties, trying to come to terms with them and what it means to live faithfully as part of the Body of Christ. It makes sense that when he started writing *Adam*, he had been struggling to write a book on the Trinity that would relate to everyday life. What does not come through in Nouwen’s telling of Adam’s story, however, is consistent real interest in Adam beyond his impact on Nouwen. It has captured many people’s imagination who do not have personal experience with individuals with profound disabilities. However, it is a perspective that still sees them as *other*.

After Adam died, Henry told Adam’s brother, Michael, that he “really hope[d] God is going to give Adam a new body, so that he can walk all around in heaven and speak, and talk with his grandpa and grandma and his uncle, who are already there.”²⁷⁰ Nouwen seems to presume that Adam’s relatives did not value Adam as he was, but I suspect he was again projecting his own needs in the statement.

E. Some Thoughts on the Shadow Narrative

Exploring Nouwen’s narrative about Adam highlights the troubling consequences for individuals with IDD when they are treated as a blank slate for personal projections. Because of Nouwen’s stature in the pastoral academic arena, he has done much to

²⁶⁹ Nouwen, *Adam: God's Beloved*. p. 78.

²⁷⁰ *Ibid.*, p. 104.

advance the sentimental strands of the *shadow narrative*. I identified a consistent group of narrative threads that have been told throughout the course of pastoral activity in the US Catholic Church regarding persons with IDD. These narratives can seem to have positive intentions by offering protective or “special” treatment, because they are innocent, perpetual children, “people of the heart,” a source of inspiration by their fortitude, or an opportunity for others to become better people. Or the narratives can be openly negative and even hostile. The mindsets within the narrative threads have been observed in studies on the participation of individuals with IDD in Catholic parish life, including their impact on Catholic clergy’s expectations and pastoral practices.²⁷¹

I did not discover these themes; they have been operative regarding vulnerable and marginalized groups of people throughout history and are noted within models of disability. What I have done is to recognize a consistent pattern that weaves the main threads together into one over-arching narrative about persons with IDD that I have named the *shadow narrative*. The value of this is to bring what was hidden into the light, as the *shadow narrative*, to identify its true intent and impact. Not unique to the Catholic Church, vulnerable individuals have been devalued and marginalized throughout human history, justified by the *shadow narrative*, though not named as such.

Brought into the light, the Church, as the body of Christ, can seek to correct this, remembering the shared vocation to reflect the image of God into the world.²⁷² To be faithful to this vocation, it needs to continue to ever renew itself forward, led by the Spirit so that, together and individually, it is to be credible to its word. Changing these trends that have provided such an eclipse of the light for so long will require significant intentionality. Such change will require nothing short of a cultural shift, actually forming a new culture. In this culture, all will be equally valued within an interdependent community. Such was the vision of the Second Vatican Council,

²⁷¹ Mazna Patka and Katherine E McDonald, "Intellectual Disability and Faith Communities: Perspectives of Catholic Religious Leaders," *Disability & Society* 30, no. 8 (2015): pp. 1241-1258.

²⁷² Catholic Church, *CCC*, 1877.

The social order requires constant improvement: it must be founded in truth, built on justice, and enlivened by love: it should grow in freedom towards a more humane equilibrium. If these objectives are to be attained here will first have to be a renewal of attitudes and far-reaching social changes.

The Spirit of God, who, with wonderful providence, directs the course of time and renews the face of the earth, assists at this development. The ferment of the Gospel has aroused and continues to arouse in human hearts an unquenchable thirst for human dignity.²⁷³

This will not be an easy transition. Both the Council Fathers and the US Bishops indicate the need for intentional planning and education of the full church.²⁷⁴ Within the *US Pastoral Statement*, the bishops clearly put the focus of attention on the Church at large. They recommend programs of formation for parishes, clergy and seminarians to change the attitudes and prejudices of the general community about persons with disabilities, so the Church may truly become the interdependent people the US Bishops calls it to.²⁷⁵ Yet, in reality, at the local level, attention is usually focused on persons with disabilities. What do *they* need so that *they* can fit in?

Jason Greig tackles a similar challenge in *The disarmed community* that could be instructive. Greig seeks to develop a framework for an ecclesiology that moves beyond inclusion and could be compatible with different societies.²⁷⁶ He unpacks L'Arche culture to identify how to develop one for a new peace ecclesiology where persons with IDD are

²⁷³ Council Fathers of Vatican II, "Pastoral Constitution, Flannery," par 26.

²⁷⁴ Need to find quotes references. Already mentioned.

²⁷⁵ USCCB, "US Pastoral Statement," par 5, 13.

²⁷⁶ JFR Greig, "The Disarmed Community: Reflecting on the Possibility of a Peace Ecclesiology in the Light of L'arche," (2018): p. 8, 130-144, 165. In an earlier draft of this text, I referred to the culture as envisioned by Jean Vanier. Per my earlier reference about Vanier revelation, I think it is safe to say we really cannot know what he envisioned. However, Greig is well acquainted with L'Arche culture as he was an assistant for a number of years. So, he is qualified to speak from his own experiences of L'Arche culture and his work should not be lost. Therefore, I will refer to Greig's interpretations. In chapter five I will express my own concerns about Vanier's language, which I have noted long before the revelations, though I never imagined what has been revealed.

equally valued, and feel a sense of belonging.²⁷⁷ Greig speaks of building a culture that goes “beyond inclusion,” that facilitates real opportunities for mutual transformations through manifestations of the Spirit.²⁷⁸ Through studying the development, practices, habits and attitudes of L’Arche communities that live according to Vanier’s theology, Greig discerns its associated culture. Within these Greig notes that this culture disarms the typical western habit to force change due to some perceived deadline, thus allowing possibilities for the activities of the Spirit within the community. Disarmament becomes his hermeneutical key, and patience the foundational habit for his peace ecclesiology. Respectfully done, patience disarms the typical western habit to force change due to some perceived deadline, rather than allowing possibilities for the activities of the Spirit within the community.²⁷⁹ Greig’s search for a culture that is beyond inclusion echoes Reynolds’ counter to the *cult of normalcy*, denying gate keepers and opening up spaces for mutuality and vulnerability, in the spaces in between each other, where the Spirit can be manifest.²⁸⁰

The charity thread is particularly problematic, because it depends on outdated information about persons with disabilities and, more importantly, it misconstrues understandings of charity that directly contradict belief in the innate dignity of every person and commitment to human flourishing. Also, OTM becomes a sentimental place for idealized acceptance and personal transformation for people of the normative culture, through patronizing platitudes at the expense of vulnerable individuals. It implies that Christ can only be found in the people on the margins. It is important to remember that the face of Christ can be found in every person, whether they are on the margins, in the center, or any place in between.

²⁷⁷ Ibid., pp. 7-10.

²⁷⁸ Ibid., 165.

²⁷⁹ Ibid., pp. 161-165.

²⁸⁰ Reynolds, *Vulnerable Communion: A Theology of Disability and Hospitality*. L1862.

To succeed where others have failed, it is important to more fully understand the dynamics at play. This will be necessary to effectively respond to the US Bishops challenge in the *US Pastoral Statement*, to re-educate all within the church and become “a community of interdependent people and discover the Kingdom of God in [its] midst.”²⁸¹ Understanding the past can facilitate understanding the present location, and provide very important information for charting a new course. Some of that has been done in this chapter by casting a light on the *shadow narrative* and opening up long held traditions for reassessment. Because of the prominence and persistence of the charity thread within the *shadow narrative*, more information is needed about its practice. In the next chapter I will look into charity’s development in history to identify moments that have disconnected it from its roots, redirecting it toward self-serving utilitarian motives, such as the examples shared in this chapter.

²⁸¹ USCCB, “US Pastoral Statement.”

IV. What Happened to Charity?

Are there no prisons?' asked Scrooge. ... 'And the Union workhouses?' demanded Scrooge. 'Are they still in operation?' ... 'The Treadmill and the Poor Law are in full vigour, then?' said Scrooge. ... 'Oh! I was afraid, from what you said at first, that something had occurred to stop them in their useful course,' said Scrooge. 'I'm very glad to hear it.' ...

I help to support the establishments I have mentioned -- they cost enough; and those who are badly off must go there.'

~ Ebenezer Scrooge, *A Christmas Carol*²⁸²

The last chapter followed the trail of the *shadow narrative* throughout ecclesial documents and moments in ministry with persons with disabilities in the US Catholic Church. I identified five different threads of this spectral force, and how it serves to create a place called, *On the Margins*, as it devalues and marginalizes groups of vulnerable individuals. This is an unconscious process, which can even influence people who should know better. I want to spend more time investigating the roots of the charity thread because of its predominance and problems. There is a model of disability, simply known as the charity model, that influences the thread, so it will be helpful to reference as well. Models and their place in disability discourse was briefly introduced in chapter one. The charity model is based on the long-standing stereotypes of dependency, sentimentality, and otherness that portray individuals with disabilities more as objects of pity and instruments for others to become better people. This generates narratives that discount them as persons who have abilities to contribute to the community.

Such was the interpretation of the message from Pope Francis' twitter account, "People with Disabilities are a gift for the family and an opportunity to grow in love,

²⁸² Charles Dickens, *A Christmas Carol*, (August 11, 2004; London: Chapman & Hall, 1843), <https://www.gutenberg.org/files/46/46-h/46-h.htm>.

mutual aid and unity.”²⁸³ The tweet referenced his recent papal exhortation, *On Love in the Family* in which he discussed individuals with disabilities within four paragraphs that he addresses the impact of having a child with a disability on a family, the Church’s gratitude for families affirming the dignity of life by accepting their child with a disability; the fraternity and affection of siblings toward the disabled “little brother or sister,” and the need for extended family support.²⁸⁴

David Perry, the father of a boy with Down Syndrome responded critically,

both this tweet and its broader context render the disabled family member as object rather than agent, as an opportunity for the able person to demonstrate their goodness rather than a person who might do good themselves, and perpetuate the myth of the disabled individual as eternal child. Although charitable in sentiment and kind intention, such paternalism isn’t what disabled people really need.²⁸⁵

Perry clearly agrees with our previous assessment that such sentiments undermines professed statements about human dignity and the importance of opportunities for meaningful engagement within all areas of community life. Although he notes Pope Francis’ good intentions, yet that does not mitigate his discontent. As such, his reference to charity reflects a curious phenomenon regarding contemporary views. It is both used to highlight a benevolent sentiment towards vulnerable people, and at the same time replaced by the notion of justice as the more appropriate response to their vulnerability. Perry seems to acknowledge charity as a positive intention, whereas at the same time, call it paternalistic. Having been a key notion in Catholic moral thinking for 2000 years, charity has now been thrown in disrepute. This observation raises the question addressed by the present chapter: What happened to charity? Perhaps

²⁸³ Pope Francis, "Tweet-People with Disabilities Are a Gift," <https://twitter.com/pontifex/status/718710082406473728>.

²⁸⁴ *Amoris Laetitia* (the Joy of Love), (Beacon Publishing: Libreria Editrice Vaticana, 2016). par 47, 195, 197.

²⁸⁵ David Perry, "'Amoris Laetitia' Reflects Narrow View of Disabled Persons," CRUX, <http://www.cruxnow.com/church/2016/04/12/amoris-laetitia-reflects-narrow-view-of-disabled-persons>.

exploring the historical development of charity will yield clues about the source of its fallen reputation and indicate differences between the pretense of charity in the *shadow narrative* and authentic charity. This *umbrage* casts a particularly long and pervasive *shadow* that not only obscures individuals with disabilities, but the Gospel as well. This backward glance may guide an appropriately informed response to our problem.

A. The Complaint About Charity

The word charity today is associated with either an institutional activity or, to paraphrase Perry, an opportunity for people without disabilities to demonstrate their goodness, or even to develop goodness, and presumes that persons with disabilities and other marginalized individuals are unable to develop skills or do for themselves. While they could be mutually supportive, supporting charitable activity by institutions is perceived as a way for people to ‘do good things,’ from a distance, without making personal contact.

Floris Wood, the husband of Renee Wood, a blogger and woman who has cerebral palsy, is often approached by strangers, much to their chagrin, when they are out and about. These people know nothing about Floris and Renee, but praise and bless him for being with Renee. Kayla Whaley, a writer who has a disability, also strongly rejects the implications of Pope Francis’ tweet, which “sees us less than human,”²⁸⁶ and says further, “We are not ‘gifts’ or ‘opportunities’ to ~teach abled people

²⁸⁶ Kayla Whaley, “Disabled People Are People: A Message to the Pope,” in *Telling your followers to view us as objects that exist for the edification of abled people, tells them we're less than human*, @Pontifex., ed. @PunkinOnWheels (2016).

about love~.”²⁸⁷ Perry, Whaley and the Woods rightly reject naming the value of individuals with disabilities in its instrumental effect on others, which locates the value of a person outside of themselves. This not only denies the innate dignity of every person, but as Hans Reinders correctly points out, the positive response depends on the other person’s moral orientation.²⁸⁸

Perry wonders if there is a more helpful way to understand disability that includes a built-in framework of respect for all individuals with disabilities as persons of interest and concern, rather than objects for the benefit of others. Perry wonders if there is a theology on disability that “would open pathways to witness and embrace our shared humanity, regardless of the functioning of our bodies and minds, and understand that all of us need the opportunities to be both actors and be acted upon as we pursue a good life in our communities?”²⁸⁹ It’s a great question! Catholic Social Teaching and the US Bishops *Pastoral Statement* certainly seems to, yet there continues to be frequent lapses in Church statements and pastoral experiences.²⁹⁰ Historical exploration has helped me so far in understanding present dilemmas, so with the same inclination, I will turn to particular moments in the charity tradition.

²⁸⁷ "Disabled People Are People: A Message to the Pope," in The Pope tweeted about disabled people as gifts and opportunities for abled people. I responded. Then the pushback to my call out started.

Disabled people are PEOPLE. Full stop. We are not "gifts" or "opportunities" to ~teach abled people about love~, ed. @PunkinOnWheels (2016); The Pope tweeted about disabled people as gifts and opportunities for abled people. I responded. Then the pushback to my call out started. "Disabled People Are People: A Message to the Pope," self, <https://storify.com/PunkinOnWheels/disabled-people-are-people-a-message-to-the-pope>

²⁸⁸ Hans S. Reinders, *Receiving the Gift of Friendship* (Grand Rapids: Wm. B. Eerdmans Publishing, 2008), pp. 280-283.

²⁸⁹ David Perry, "Pope Francis Needs to Do More Than Kiss the Disabled," CRUX, <https://cruxnow.com/vatican/2016/06/14/pope-francis-needs-kiss-disabled>.

²⁹⁰ Besides this current quote, I have shared a number of examples throughout the text.

B. Exploring Charity

The charity model as it stands undermines respect for human dignity, which all of Catholic Social Teaching is based on. But what if charity has been misconstrued? Going back in time may help to understand developments today that grew out of earlier events. This will not be an exhaustive historical expose, but enough to notice shifting trends that may suggest emergent patterns associated with questions of today. Because the Hebrew Scriptures and culture influenced the Christian charity tradition received from Christ, it is important to consider the Gospel in light of its Jewish roots as well.

1. Jewish-Christian Charity

Jewish practices for charity prior to the fourth century, C.E. were concerned with attending to physical sustenance needs, as well as for personal and social impacts of poverty. They were organized to maintain the privacy of the individuals served and do away with public begging.²⁹¹ This served both respect for persons receiving charity and also the good of the community. However, during the fourth century, both Jewish and Christian ecclesial charity structures began to consolidate economic, political and religious power.²⁹²

²⁹¹ Gregg E Gardner, *The Origins of Organized Charity in Rabbinic Judaism*, (New York: Cambridge University Press, 2015). pp. 8-10.

²⁹² For more information about these parallel developments in charity, see Gardner, *The Origins of Organized Charity* and Helen Rhee, *Loving the Poor, Saving the Rich: Wealth, Poverty, and Early Christian Formation*, Grand Rapids, MI: Baker Books, 2012. Kindle. Both authors provide extensive background about the views on poverty, wealth, and social justice in Jewish texts and Christian texts in Jesus' day and contrast it with Greco-Roman philosophies. Both books provide helpful insight into this area, including suggestions for implications on Patristic conversations on charity.

2. *Diaspora and Greco-Roman Influences*

As Christianity and the Jewish Diaspora spread, they encountered Greco-Roman philosophies about wealth, poverty and social order that lacked an appreciation for Yahweh's covenantal relationship with the people of Israel, and its underlying concern about people who are marginalized and vulnerable.²⁹³ Over time such influence can be discerned in Christian practice of almsgiving as acts of kindness became oriented for personal redemption, rather than kindness from concern for the good of the community.

Wealth, status, good health, beauty and skills received from God were to be used in service of God, but attitudes about wealth and poverty have been a bit convoluted. Therefore, sharing with those in need with humility and charity [love] is no cause for a sense of pride in ownership or ability. Divine purpose was seen in all of life, which is reflected in the following quote from St. Basil.²⁹⁴ "If you acknowledge your possessions as coming from God, is He unjust because He apportions them unequally? Why are you rich when another is poor, unless it be that you may have the merit of a good stewardship, and he the reward of patience?"²⁹⁵ This recalls Jesus' identification *with* the poor in Mt 25: 35-45, "whatever you did for one of these least brothers of mine, you did for me" and Lk 6:20, "Blessed are you poor, for yours is the Kingdom of God." According to Jacques Dupuis, Jesus goes beyond calling us to a preferential option for the poor, and to also identify with the poor.²⁹⁶ Yet, Basil's text also reveals an

²⁹³ Helen Rhee, *Loving the Poor, Saving the Rich: Wealth, Poverty, and Early Christian Formation* (Baker Books, 2012), p. 27.

²⁹⁴ Benedict of Nursia, "*RB 1980: The Rule of St. Benedict in English*," ed. Timothy Fry, OSB (Collegeville, MN: Liturgical Press, 1982).RB 2:2; 4:21; 5:2, 53:1, 72:11.

²⁹⁵ F.L.B. Cunningham, *The Christian Life*, (Eugene, OR: Wipf & Stock Publishers, 2010), <https://books.google.com/books?id=d3VMAwAAQBAJ>. Google Books. p. 420.

²⁹⁶ Jacques Dupuis, *Who Do You Say I Am?: Introduction to Christology* (Orbis, 1994), p. 51.

instrumental purpose for vulnerable individuals, to provide for the benefit of those with more status or power in a community.

Gregory of Nyssa provides a more helpful quote that affirms our connection with each other through our humanity. It verifies that disability, illness and vulnerability are shared as part of the human condition and that they are contingent characteristics, rather than constitutive of us. "Don't count too heavily on the future. In condemning the sickness that preys upon the body of this man, you fail to consider whether you might be in the process condemning yourself and all nature. For you yourself belong to the common nature of all. Treat all therefore as one common reality."²⁹⁷ An essential attitude of Judeo-Christian charity acknowledged that all abilities, possessions and station belonged to God, as their source, and all were for the service of God. Through two layers of institutionalization, in the fourth century and the Carolingian reorganization of the Middle ages, it would seem to have lost its connection with love in its vernacular understanding and is often perceived as patronizing and self-serving.

3. *The Rule of St. Benedict*

Another branch of charitable activity was also developing around this time in monasteries. Christian monasticism existed for approximately 200 years by the time St. Benedict of Nursia, popularly considered the "Father of Monasticism," wrote *The Rule of St. Benedict* (*The Rule*) and indirectly strongly influenced the next turn of charity under consideration.²⁹⁸ The early tradition originated as a prophetic voice and corrective to society in the East, and migrated to the West by St. John Cassian. Benedict was heavily influenced by the writings of Saints Augustine, John Cassian, Basil, Gregory of Nyssa and of Nazianzus. Jewish influences can be discerned through the lens of the Gospel in

²⁹⁷ Gregory of Nyssa, "On the Love of the Poor: 2 ". Translated by Susan R. Holman; in Susan R Holman, "Three Sermons," in *The Hungry Are Dying: Beggars and Bishops in Roman Cappadocia* (Oxford: Oxford University Press, 2001; reprint, November 2003), Appendix.

²⁹⁸ Timothy Fry, OSB, ed. *RB 1980: The Rule of St. Benedict in Latin and English with Notes* (Collegeville, MN: Liturgical Press, 1981), p. 3.

their work, in a countercultural testament against society's treatment of people who were marginalized, as well as concern for travelers and strangers.²⁹⁹

Benedict did not intend to start a widespread movement. He was only concerned with his monks at Montecassino and codified a simple path to holiness, what he called a "little rule for beginners," so they could serve the world through prayer and charity. Benedict drew from various Rules and there continued to be others for other monasteries, for quite a long time. Another rule from the 6th century heavily influenced *The Rule*, known as *The Rule of the Master (RM)*. Authorship of *RM* and exact date is unknown, but its influence on it is well documented in monastic scholarship.³⁰⁰ In fact, until the 1930's *The Rule* was thought to predate *RM*, partly because it is much briefer and simpler than *RM*. This discovery initially caused much controversy in the Benedictine community, because what was considered to be precedent setting was now discovered to be an imitator. However, upon further reflection and analysis, Benedict's contribution was again appreciated for its faithfulness to tradition and its simplicity.³⁰¹

Whereas *RM* included many details about what to do in a vast assortment of situations, *The Rule* focuses on principles to guide his monks. It reflects trust in the abbot's ability to respond to the specifics of situation and demonstrates more concern for inner orientation than outward conformity that lacks authentic feeling. Additionally, *The Rule* brings a realized eschatology into the monastery's purpose, with an emphasis on perfect charity. Perfect charity requires the humility which realizes "submission to the

²⁹⁹ Mayeul de Dreuille, O.S.B., *The Rule of Saint Benedict: A Commentary in Light of World Ascetic Traditions* (Mahwah, NJ: Paulist Press, 2002), p. 238, 316-318. The prophetic texts: 2 Sam 12: 1-6; 2 Kings 4:13; Amos 5, etc. The importance of hospitality in Lev 19:34; Deut 10: 17-19.

³⁰⁰ Fry, *RB 1980 with Notes*, pp. 65-96.

³⁰¹ *Ibid.*, pp. 71-73, 84.

action of grace within,” so empty acts of kindness would not have provided paths to holiness.³⁰²

Monastic life was divided into three activities: common prayer, *lectio*, and work. The purpose of work was to support the basic needs of the monastery and almsgiving for people in need: travelers, people who were poor, victims of circumstance, such as widows and orphans, and guests. All were to be received as Christ.³⁰³ Chapter four, which provides guidance for ‘good works’ indicates the heart of service and life of the monastery. The first two directions illustrates the essence of monastic life’s purpose: “1 First of all, love the Lord God with your whole heart, your whole soul and all your strength, 2 and love your neighbor as yourself (Mt 22:37-39; Mark 12:30-31; Luke 10:27).”³⁰⁴ Benedict placed an emphasis on the fraternal relationships among the monks, and promoted the evangelical value of the monastery as a ‘fraternal communion in love,’ reflecting Augustine’s influence. While vertical relationships of respect were important, the emphasis was on the community as a whole.³⁰⁵

From the beginning monastic spirituality was firmly grounded in scripture with the practice of *lectio divina*, which informed their life in community. Some of the scripture sources for Benedict, as well as the earlier monastic traditions provide insight into monastic purpose and identity.³⁰⁶

³⁰² Ibid., pp. 93-94; Adalbert de Vogüé, *The Rule of Saint Benedict: A Doctrinal and Spiritual Commentary*, trans. John Baptist Hasbrouck (Kalamazoo, Michigan: Cistercian Publications, 1983), pp. 22-24.

³⁰³ Fry, *RB 1980 with Notes*, pp. 65-96.

³⁰⁴ Benedict of Nursia, "*RB 1980 in English*," pp. 26-27.

³⁰⁵ Fry, *RB 1980 with Notes*, p. 93.

³⁰⁶ de Dreuille, *The Rule of Saint Benedict: A Commentary in Light of World Ascetic Traditions*, pp. 316, 320, 318, 319. Scripture text will be from de Dreuille. Page sources are listed in order.

Lev 19:34 The stranger who sojourns with you shall be as the native among you, and you shall love him as yourself, for you were strangers in the land of Egypt

Acts 4: 32-35 They had everything in common ... There were no needy persons among them ... distribution was made to each according to need.

Lk 14: 13-14: When you give a feast, invite the poor, the maimed, the lame, the blind, and you will be blessed, because they cannot repay you. You will be repaid at the resurrection of the just.

Mt 10: 40-41: He who receives you receives me, and he who receives me receives him who sent me. He who receives a prophet because he is a prophet shall receive a prophet's reward, and he who receives a righteous man because he is a righteous man, shall receive a righteous man's reward.

Mt 25: 35 ... 43: What you did to the least of my brethren, you did it to me.I was a stranger and you welcomed me ... I was a stranger and you did not welcome me.

The text above reflect central themes of concern in monastic life: hospitality, identity with strangers, concern for people who are vulnerable and in need, and recognizing that Christ is present in every person. To the monks in Benedict's day, Christ was present in the Abbot, the monks, the guests and those who were sick or poor.³⁰⁷ Benedict included a doorkeeper, just as *RM* did, who greets visitors and assesses who they are and their needs. The doorkeeper, or porter, informs the abbot about any who need to come inside. All the monks participated in the welcome ritual of foot washing, but first they would pray to ward off any illusions of the devil. The prayer both protected the monks and provided a gift to the guest. The ritual foot washing served as a sign of both humility and communion.³⁰⁸ Contrary to *RM*, Benedict was more concerned with the heart of the doorkeeper, to be able to respond appropriately to guests' needs. The monastery's door was always open, in that the porter was always available to answer it. Mayeul de Dreuille notes that Benedict added two important dimensions in *The Rule* regarding hospitality. Pachomius and Cassian only applied Mt 25:35 to receiving other monks,

³⁰⁷ Benedict of Nursia, "*RB 1980 in English*." RB 2:2; 4:21; 5.2; 53:1; 72:11. *RB* 2:2; 4:21; 5.2; 53:1; 72:11.

³⁰⁸ de Dreuille, *The Rule of Saint Benedict: A Commentary in Light of World Ascetic Traditions*, p. 330. De Dreuille says "fraternal charity", which I replaced with communion, as widows and families were also welcomed.

whereas Benedict welcomed all, as if receiving Christ. Also unique in *The Rule* was to allow interaction, though limited, between monks and guests.³⁰⁹

According to de Dreuille, hospitality in *The Rule* also extended to heretics.³¹⁰ He cites Gregory the Great in *Dialogues* II: 15, 31 for this. Neither Fry nor de Vogüé include heretics in Benedict's hospitality. Fry specifically discounts their inclusion. Heretics in Benedict's day would most likely be Arians or non-Christians and he doubts they would have been received. Fry acknowledges earlier that Gregory the Great was the only contemporary of Benedict to mention him, and does not discount the essence of what he says about Benedict, even if it cannot be taken literally. Gregory's intent, Fry says, is to demonstrate "the working of God in a man's life." Though it is not easy to separate fact from the symbolic and imaginative, he says that "symbolism, however, does not exclude historicity."³¹¹ Considering this, it seems reasonable to accept de Dreuille's opinion that heretics would not be excluded from Benedict's hospitality.

Within the monastic system, the monastery is the *house of God* because of the "perfect presence of Christ as all in all, in the one who welcomes and in the one who is received," which is captured in the metaphor of "the two faces of Christ." One opens and gives; the other knocks and makes himself a beggar. In this we see the role of beggar as a metaphor applied to whoever was receiving. The proximity of the guest area and staffing is considered so that travelers may be welcomed at any time of the day or night. Guests ate at the abbot's table, away from the monks, so they would not be tempted during times of fasting. Travelers were not subject to fasting, because they needed

³⁰⁹ Ibid., pp. 330-32.; Fry, *RB 1980 with Notes*, pp. 183, 255-259.

³¹⁰ de Dreuille, *The Rule of Saint Benedict: A Commentary in Light of World Ascetic Traditions*, p. 330.

³¹¹ Fry, *RB 1980 with Notes*, pp. 256, 73-76.

sustenance to support their journey, as did people who were poor or infirm. It is important to note, that hospitality was more important than the abbot observing fasts.³¹²

Charity according to Benedict was rooted in holy obligation, it was to be done with humility within relationships and acts of service, amongst the monks and between the monks and guests. Someone's need was the guide for distribution, not rank or status, though someone's condition in life was taken into consideration when providing assistance.³¹³ Even wealthy travelers were considered vulnerable, due to the conditions of travel in Benedict's day. Benedict considers the varying needs of the diversity of guests they served, which included travelers from all stations of life, as well as people who were poor, ill or had a disability.³¹⁴

4. *The Holy Roman Empire*

Benedict's monastery wasn't the only option in its day, nor the predominant one until outside events changed its course. Charlemagne, the Frankish king, was crowned Emperor of Rome by Pope Leo III in 800. When he unified the Catholic Church in Europe within a feudal society based on previous imperial models, it combined ecclesial and political structures to bind the empire, "ruling through 'a managerial aristocracy' composed of powerful laymen, bishops and great abbots."³¹⁵ In the seventh and eighth centuries, it was difficult for the pope to effectively relate to churches outside of Italy. "In the Carolingian church ... one Christian society was ruled by a Christian king or

³¹² de Dreuille, *The Rule of Saint Benedict: A Commentary in Light of World Ascetic Traditions*, pp. 331-333.

³¹³ Fry, *RB 1980 with Notes*, p. 233.

³¹⁴ Benedict of Nursia, "*RB 1980 in English*." Though this is woven throughout RB, particularly helpful examples are RB 4:1-78; 7:1-70; 71:1-9; 72:1-12; 31:1-19; 32:1-5; 34:1-7; 53:1-23.

³¹⁵ Roger Haight, SJ, *Christian Community in History* hardcover ed., vol. Historical Ecclesiology (New York, London: Continuum, 2004), p. 271.

emperor with the bishops.” The pope did not have the autonomy of previous popes, but he now had the backing of the emperor.³¹⁶

Charlemagne encouraged monasteries to follow a single rule, *The Rule of St. Benedict*, but it wasn’t until his son’s reign, Louis the Pious, that this really gained momentum. He established it as *The Rule for the Holy Roman Empire* at the Councils of Aachen of 816 and 817.³¹⁷ Although care for vulnerable people was part of the work of the Church prior to this, it was somewhat loosely managed through bishops. Monastery involvement was handled independently. There were other systems as well, but nothing unified.³¹⁸ Now, *The Rule* was promoted and adopted as the ideal rule through the efforts of Benedict of Aniane and Smaragdus, abbot of St. Mihiel.

a. Increasing Rigidity

Its simplicity was *The Rule*’s original appeal, but the amount of discretion it privileged to the abbot was problematic within this new structure. Though the monastery still was a place for the monks to seek God through prayer, asceticism and liturgical service, it was also “an organ of the Christian state: the abbot became an important political functionary, the abbey was a powerful economic force, and the state assured control by reserving the right to appoint the abbot in most cases.”³¹⁹ This new identity and structure was the first change during this time which impacted Christian charity tradition.

³¹⁶ Ibid., pp. 268-272.

³¹⁷ Daniel M. LaCorte, "The Expositio and Monastic Reform at Cîteaux," in *Commentary on the Rule of Saint Benedict, Smaragdus of Saint-Mihiel* (Kalamazoo, MI: Cistercian Publications, 2007), p. 11.

³¹⁸ Michel Mollat, *The Poor in the Middle Ages: An Essay in Social History* (Yale University Press, 1986), pp. 31-38.

³¹⁹ Fry, *RB 1980 with Notes*, p. 123.

To compensate for the amount of discretion *The Rule* provided, supplemental documents were written to provide additional guidance on discipline and liturgical practice, as "customaries" or "statutes." Two texts that were highly referenced from this time were *Concordia Regularum* by Benedict of Aniane and the first full recovered *Commentary on the Rule of Saint Benedict*, by Smaragdus abbot of St. Mihiel in Lorraine, from the early 9th century. Benedict's *Concordium* was to validate the firm foundation of *The Rule* within monastic tradition and the commentary by Smaragdus was to provide additional insights for the day on its use.³²⁰ Smaragdus' commentary grew out of the Monastic Capitulary of 817, which dictated that abbots should contemplate upon the *Rule* "word for word" for proper comprehension to live out with their monks.³²¹ Although Benedict of Aniane and Smaragdus were pious men, monastic life and the organization of charity was now integrated within the Holy Roman Empire.³²² Changes in society that influenced monastic life during the Middle ages could have impacted its tradition of charity and hospitality.

b. Latin Became Language of the Monks

Another significant shift within the Carolingian Empire was the displacement of Latin in larger parts of society by vernacular language. Latin remained in liturgy and prayer, which meant that it was mostly only restricting clergy and monks who understood it. Also, the monks were increasingly involved with academic work transcribing and writing, leaving little time to care for travelers and vulnerable people.

c. Expanding Institutionalization

This meant that the work of and for the monastery would need to be done by other people. A group of laymen were admitted to religious life by establishing a new role of *conversi*. Their identity was a bit confused within the order, not really equivalent

³²⁰ Ibid., pp. 121-124.

³²¹ LaCorte, "The Expositio and Monastic Reform at Cîteaux," pp. 10-12.

³²² Fry, *RB 1980 with Notes*, p. 123.

to a religious brother today. *Conversi* were typically uneducated and didn't speak Latin nor participate in the liturgical life of the monastery. Their vocation was to serve the monastery in its sustenance and service, often keeping them away from the monastery all week, only returning on Sunday. This meant that those devoted to prayer were no longer connected with works of charity, with welcoming Christ in the guests of the monastery, the travelers, the poor, the elderly, etc. This work was now done by the *conversi*, introducing a hierarchical order of holiness within it, though it was only later that they were considered second class monks of sorts.³²³

Although there were exceptions, monastic life continued to change and the "religious culture of 12th century degenerated into mediocrity and sometimes ignorance," according to Thomas Fry, a Benedictine scholar, which also did not help the experience of charity at the time.³²⁴ Through the division of responsibilities, the work of charity was being assigned to men disconnected from its spiritual roots, the work of charity was being done without the heart of charity, foreshadowing later developments in charity. As Fry noted, the integration of monastic charity within the structure of the Empire "was to have disastrous consequences."³²⁵

It is helpful to recall there were different motivations for religious life throughout the Middle Ages. While there were authentic vocations, clerical life was also often the best option for the younger son of nobility or tradesmen, and also an opportunity for education and welfare for those who were poor. In later years, as already mentioned, the pastoral activity was rarely done by the "higher ranking" priests and monks. The

³²³ Ibid., pp. 128-129. The *conversi* referenced here are separate from another use of *conversi* which developed in the 11th century within Cistercian monasteries motivated by penance, and/or piety, which Fry discusses on p. 418. ; For more on the 11th century practice, see Jacques Dubois, OSB, "The Laybrothers' Life in the Twelfth Century: A Form of Lay Monasticism," *Cistercian Studies Quarterly* 7, no. 3 (1972): pp. 161-213.

³²⁴ Fry, *RB 1980 with Notes*, pp. 128-129.

³²⁵ Ibid., p. 123.

conversi could have been motivated for survival, rather than service, which could lead to a more institutionalized way to think about charity, disengaging it from the individual. Poverty, or the inability to support oneself, was more of an issue than disability. Those who bore their poverty well and quietly sought assistance were treated more favorably than those who were more problematic in behavior or attitude and more vocal about their needs.³²⁶

Remember that Benedict of Nursia only sought to provide a simple path of holiness for men and to provide hospitality for travelers, widows, orphans, and anyone else in need. While evangelical concerns about charity and communion certainly could infuse both with an instrumental nature, both charity and the way of living together in community and welcoming guests was supposed to be done with the realization of and “submission to the action of grace within him.”³²⁷ But Benedict’s “little book for beginners” became much more complicated and regulated as an arm of the Holy Roman Empire. Whereas *RB* focused on inner orientation, mutuality and trust in the abbot’s discernment, rubrics and uniformity now took precedence. Monasteries were huge in comparison to Benedict’s day. As society evolved more throughout the Middle Ages, moves from feudal to urban life significantly changed monasteries’ economics, developing clericalism in the Church, political changes, the Black Death, the Hundred Years’ War, as well as problems within monasteries continued to impact the understanding of charity.³²⁸ It is not difficult to imagine how the “two faces of Christ” could become lost in the experience of charity with the degeneration of its authentic tradition.

³²⁶ Mollat, *The Poor in the Middle Ages: An Essay in Social History*, pp. 38-53.

³²⁷ Fry, *RB 1980 with Notes*, pp. 93-94.; de Vogüé, *The Rule: A Commentary*, pp. 22-24.

³²⁸ Fry, *RB 1980 with Notes*, p. 131.

Recapping this historical review of early Christian charity highlights some influential shifts that occurred. The roots of Judeo-Christian charity acknowledges that all abilities, possessions and station originate in God, and therefore belong in service to God. However, Greco-Roman influences took seed in some areas during the Jewish Diaspora that partially solidified during consolidated organizational developments in both Jewish and Christian administrations of charity. The monastic tradition of charity which sprouted around the same time would continue to be shaped by socio-political developments throughout the Middle Ages.³²⁹

From this review the moments I find potentially most influential to this discussion are the Greco-Roman influences during the Diaspora during the apostolic period, the two rounds of centralization and institutionalization, in the fourth century and the Carolingian reorganization of the Middle ages. The recession of Latin from every day usage removed those from the practice of charity who had vowed to live it and replaced them with those most likely more concerned with survival today than salvation tomorrow. They each seem to have inserted fissures into charity's connection with love in its vernacular understanding, together making way for the patronizing and self-serving charity model known today. Another round of institutionalization in modern times that Reinders and others have noted leaves no trace of charity's basis in God's gratuitous activity amongst humanity through the Spirit.³³⁰ A reminder to the reader, this is not an exhaustive historical expose, my purpose is merely to notice shifting trends that may suggest emergent patterns associated with questions today. Next, I will unpack implications of these trends.

³²⁹ Ibid. Such as moves from feudal to urban life that significantly changed monasteries' economics, developing clericalism in the Church, political changes, the Black Death, the Hundred Years' War, as well as evolving problems within monasteries.

³³⁰ Hans S. Reinders, "What's Wrong with Charity? Considerations for a Modern Travesty of Christian Ethics," in *Say What's Up. Try Exploratory Ethics. Ceremony in Honor of Hans G. Ulrich*, ed. Gerard den Hertog, et al. (Leipzig: Evangelical Publishing House, 2017), 135-160. in author's copy 1-15.

C. Dependence vs. Flourishing

A major complaint about the charity model of disability, and thus the charity thread of the *shadow narrative* concerns the sentimental attitudes that say individuals with disabilities have a positive effect on other people's attitude and behavior overshadows them as persons and reinforces dependency. Pope Francis commented, "People with disabilities are a gift for the family and an opportunity to grow in love, mutual aid and unity."³³¹ This is probably the most difficult of all the text in his encyclical. The problem with this is that it locates the value of a person outside of him or herself and has more to do with a person's moral orientation, than with the person with a disability, as Hans Reinders correctly points out in *Receiving the Gift of Friendship*.³³² We are all called to be gift to the other, to be Christ to my neighbor and to see Christ in my neighbor. One does not need a child with a disability specifically to grow in love and reciprocity. I suggest this happens in any authentic relationship with someone who is objectively vulnerable, in which we discover our vulnerability, and allow our masks of superiority and self-sufficiency to fall away. So yes, this happens with individuals with disabilities, but not only with persons with disabilities and maybe not with all persons with disabilities. It can happen in relationships with children,³³³ as well as with individuals who allow themselves to be vulnerable and not hide behind pretenses. If we are fortunate, we are forever changed by these relationships and carry the experience forward, at least sometimes and hopefully grow in our own ability to be vulnerable and open.

As we recognize our own vulnerability and allow ourselves to be changed in the process, we can grow in our own ability to be vulnerable and to be open with others, but

³³¹ Pope Francis, *Amoris Laetitia (the Joy of Love)*. par 47.

³³² Hans S. Reinders, *Receiving the Gift of Friendship*, (B002B54G91; Grand Rapids: Wm. B. Eerdmans Publishing, 2008). L 3086.

³³³ Jean Vanier, "Living Our Faith with the Retarded Person," *NAMR Quarterly Publication* 4, no. 2 (1972): pp. 2-3.

it is not an easy journey, and in fact it can be very painful. This happened for me in my relationship with my son when he was a young child. It was powerfully transformative for me the way that Greg could hold a mirror to me that reflected my self-righteous anger, or in simple words point out basic truths of love that I was missing. However, I also experienced moments of awe at the heights I was capable of in generosity and other centeredness. From the moment of birth Greg depended on me physically for nourishment and love and guidance to navigate the world and be launched into it.³³⁴ It was also the realization that I did not have total control of the situation or of him. As a young child he was very active, extremely curious, and had strong language skills and a vivid imagination. Being Greg's mom required a lot of stamina at times, and there were moments I locked myself in the bathroom so I would not hurt him.

The epiphany for me occurred over the course of a week when Greg was four years old. One day I physically held him in a timeout during a moment of self-righteous anger. When I related the experience to someone later, he wryly pointed out that the purpose of a timeout is to be away from each other. But in that moment, I was intent on controlling him. That night while reading I happened upon a discussion on the sin of anger. I felt I was looking into a mirror and was aghast at my reflection. The next day I was determined to make it up to Greg and we went to the beach. We lived in the San Francisco Bay Area at the time and our favorite beach, typical of northern California, had rocky hiking trails interspersed with pockets of sand, a perfect place for mother and son to explore and burn off excess energy. It was April and a weekday, so the beach was deserted, except for another mother with her son we encountered while hiking. While the boys played, she and I sat on some rocks and chatted. We commiserated together about the challenges of raising sons who are very curious, intelligent, strong-willed and active.

Then I learned that she had an extreme form of scleroderma, a disease that was

³³⁴ These responsibilities were shared with my husband of course, but I was with Greg full time and experienced it rather intensely.

causing progressive hardness throughout her body. She did not expect to live beyond two more years. I could not imagine a more terrible fate, other than watching her own son die, to know that she would not see him grow up! Sad though she was, she was enjoying the time she had with him, and also talking with her husband about his future and also telling her husband to remarry when she was gone. Reflecting on her situation, which seemed cruel beyond belief, I realized how vulnerable we all are, though each in different ways. Yet we also have people in our lives who support us, and we them. As people of faith, we believe God is with us through these people, at our best, forming an interdependent communion. On that day at the beach, I felt sure God was with me there, through that other mother. I learned from her that we are not in control of life or each other, we are all vulnerable, we all need each other.

I live this imperfectly, but I am a nicer person because of being Greg's mother. Similar feelings and experiences develop for me within relationships in this ministry, but the most transformative experience for me has been being Greg's mom. It has made me more aware and inclined to opportunities for openness with others. People who are powerless can draw us out of ourselves – and thus into our self – if we are open to it. Like Jesus on the cross – radical vulnerability and openness, brings new life. Radical relationship and vulnerability is at the core of being human – reflecting the image of God. Yet there needs to be reciprocity and mutuality, it is not losing oneself in the other. Such an experience could be very disorienting. I also do not mean to imply all of our relationships are like this, but even one or two such relationships changes a person, making them more comfortable with being open to others. What is at the heart of such relationships? Pope Benedict has some very helpful and thoughtful perspectives on the importance of truth in charity.

1. Reclaiming Human Dignity

Pope Benedict XVI provides many suggestions on how fraternity and charity (in truth) can enrich the Body of Christ, in *Caritas in Veritate*. This encyclical stresses the importance of a truth in charity that views the person their fullness, as well as charity in truth which sees with the eyes of love. He also tells us that charity in truth is needed to

support human development, which is integral to a person's vocation. "Charity does not exclude knowledge, but rather requires it. ... Deeds without knowledge are blind, and knowledge without love is sterile. Indeed, the individual who is animated by true charity labours skillfully to discover the causes of misery, to find the means to combat it...."³³⁵ Therefore, if we are facing a situation with true charity, we are seeking to meet the person in love, getting to know them, gifts and interests as well as support needs, rather than forming prejudiced opinions based on diagnostic stereotypes. When considering sacrament preparation and catechesis for children and teens with autism and other intellectual and developmental disabilities, this means seeking out proven practices to support the process, rather than expecting the parents to work at home with their son or daughter, setting up a separate program that furthers isolation or worse, saying that it isn't necessary or even with purpose, if someone is not considered a person.

In fact Pope Benedict also says that, "charity in truth is a force that builds community... a fully fraternal³³⁶ community ...a fraternal communion transcending every barrier, [it] is called into being by the word of God-who-is-Love ...[its] development, if it is to be authentically human, needs to make room for the *principle of gratuitousness* as an expression of fraternity" and that isolation is one of the deepest experiences of poverty.³³⁷ The charity Benedict is talking about here is different than the *shadow charity narrative* discussed earlier. In fact, this is the point he is making. Without such charity in truth, structures tend to increase the imbalance of wealth and poverty that perpetuates dependency and devalues people. While the encyclical is mainly focused on societal and political structures, nationally and internationally, Benedict also points to the applicability to family and social communities. This suggests his concerns are equally valid for the Church to reflect on life within itself, living as the body of Christ,

³³⁵ Pope Benedict XVI, *Caritas in Veritate* (Charity in Truth), (Washington, D. C.: United States Conference of Catholic Bishops; Vatican City: Libreria Editrice Vaticana, (2009) 2011). e-book. par. 17, 30.

³³⁶ Given the history associated with the word fraternity, I chose to leave it as is, but will still comment on the need for a gender inclusive word.

³³⁷ Pope Benedict XVI, *Caritas in Veritate* (Charity in Truth). par. 34, 53.

particularly as it relates to persons with disabilities, for the purposes of the present discussion.

Where does the tendency to patronize come from? There are typically four reasons for this: disinterested in the true needs of the other; choosing responses that fulfill one's own needs; limited expectations of what individuals with disabilities are capable of, or perpetuating dependency. This last one can be a persistent issue for persons with disabilities, if their dependency is reinforcing for the other person. It feels good to be needed, to make a difference in someone's life. However, if reinforcing one's own participation, rather than seeking to empower and facilitate interaction and relationship, charity in truth is absent. This resonates with my journey as Greg's mom. He is an adult today, making his place in the world. Greg is and always has been "other," a separate person from me with his own path to follow. Yet, I have not always been appropriately aware or respectful of this. This can happen with any parent, but individuals with disabilities are particularly vulnerable to this happening. People in their lives who are supposed to empower and support their meaningful participation in the world can confuse their own personal goals with those assumed to belong to the other individual.

Benedict notes the problems charity encounters when it is emptied of meaning. His emphasis on truth helps to move beyond the subverted practice of charity, and to truly see the person and value them, rather than to project one's own prejudices, stereotypes and needs. He suggests that "truth needs to be sought, found and expressed within the "economy" of charity."³³⁸ Therefore, love formed by truth moves beyond sentimentality and emptiness, it moves beyond outdated stereotypes and prejudices.³³⁹

Further, he cites the Church's mission of truth in the world to affirm the dignity and vocation of each person, which should be informed by expert knowledge of the day

³³⁸ Ibid., par 2

³³⁹ Ibid., par 3-5, 30-32.

and proven practices and to guide the changing dynamics of society.³⁴⁰ This is a very powerful statement, Benedict is referring to personal vocation based in baptism here. This is surely a call to move beyond stereotypes and outdated portraits of people that maintain dependency at best, and undermine human development and flourishing at worst! But what gets in the way? He says that it is thwarted by “the lack of brotherhood among individuals and peoples,” and further, that reason alone is not sufficient. Reason can provide social cohesion, but charity based in mutuality and support of human development and vocation comes from God.³⁴¹

Kathleen Cahalan and Bonnie Miller-McLemore, in *Calling All Years Good: Christian Vocation Throughout Life's Seasons*, says that God calls us into the many varied vocations of our life through the people in our lives. Rather than treating vocation as a noun, Cahalan talks about the *grammar* of vocation and the doing of it, through the *call* and *response* throughout our lives.³⁴² Recalling my experiences with Greg that I shared, in love God was calling me into motherhood through him, and in love I responded to God's call through Greg. The grammar of both charity and vocation suggested by Benedict and Cahalan complement each other nicely.

In serving the common good, the needs of the community and of all within the community are important.

...To desire the *common good* and strive towards it *is a requirement of justice and charity*. ... The more we strive to secure a common good corresponding to the real needs of our neighbors, the more effectively we love them. Every Christian is called to practice this charity, in a manner corresponding to his vocation ... charity, no less excellent and effective than the kind of charity

³⁴⁰ Ibid., par. 8, 9, 11.

³⁴¹ Ibid., par. 19. As noted above, given the history associated with the word fraternity, I chose to leave it as is, but will still comment on the need for a gender inclusive word.

³⁴² Kathleen A Cahalan and Bonnie J Miller-McLemore, *Calling All Years Good: Christian Vocation Throughout Life's Seasons* (Wm. B. Eerdmans Publishing, 2017), pp. 12-37.

which encounters the neighbor directly, outside the institutional mediation ...in a way to shape the *earthly city* ... a *prefiguration of the undivided city of God*.³⁴³

Echoing Pope Paul VI's social teaching, he then declares the importance of the Church to foster society animated by love, working for the "unification of humanity and the Christian ideal of a single family of peoples in solidarity and fraternity."³⁴⁴ There can be no separation between life ethics and social ethics, human dignity cannot be touted in general by words, and then in particular situations treat people differently, denying this, particularly people who are marginalized. Paul and Benedict are not distinguishing between institutional and personal actions. And they are also reinforcing the pronouncement of the Council Fathers at Vatican II already discussed. For the Church to foster a society animated by love, it needs to live that love within parish life, fostering a culture of *koinonia* that spills out into society through the individual lives of its members, to become leaven for society (Mt 13: 33). If this is to happen, it must be experienced within the congregation, both directly and through observation of how others are treated. Such cannot be legislated. Though laws and guidelines are helpful, charity comes from an inner disposition. This is the next topic for discussion.

2. *What About Rights?*

The case of one pastor's response, which contradicts the Church's mission in this regard, can make the point here. Individuals with mobility disabilities tend to sit in the back of this church, because it is closest to the main entrance and the ramp. The practice had been for a minister of communion to bring them communion first, before general distribution would start. But the pastor decided that they should sit up front, so communion for 'the rest of the church' would not be held up.' This reason was never shared with them. The Church is very long, so it is a bit of a hike getting to the front after having navigated the ramp into the building and a number of people did not want to do this. Their alternative was to wait and receive communion from the presider as he exited

³⁴³ Pope Benedict XVI, *Caritas in Veritate (Charity in Truth)*. par 7.

³⁴⁴ *Ibid.*, par. 13.

the church, in other words, *after* mass was *over*. Such a practice contradicts any sense of respect and love within the body of Christ. In talking with this pastor, he thought he was providing a solution that was in the best interests of the community. It did not register with him that the individuals with disabilities would feel marginalized within the body of Christ by his plans. They would need to either make the longer walk or wait until after the final blessing for communion. The people who complained were just ‘fighting change,’ he thought.

This is a good illustration of the legalism that Hans Reinders warns against in “What’s Wrong With Charity?” The pastor above knew those with developmental and mobility disabilities have a right to be there and receive communion, but he assumed their presence and participation should not provide any inconvenience for others.

The rights of citizenship empower people to get access to open up spaces that hitherto were closed to them. That is why they are of utmost political importance. But for any human person it takes good companions and good companionship to be able and learn to enjoy these spaces in ways that are truly beneficial. ... to expose charity’s corruption in the form of demeaning, condescending, and paternalist treatment has been necessary. What tends to be forgotten, however, is that rights can correct the perversions of charity, but they cannot restore its original spirit of good will.

From the perspective of Christian faith the loss is even more significant. ... [it] displaces the primacy of God’s act. It tends to obscure that charity as God’s friendship is what we have received before we are asked to extend it to others.³⁴⁵

While supporting each other, reaching out to each other, it is to be done in love, valuing the person. But, as Reinders reminds us, this originates through the manifestations of the Spirit, made present in the spaces within interactions with each other that transforms us. Otherwise the support risks being paternalistic, demeaning and maintaining dependence. The self-serving could take the form of considering one’s own interests, or those of a particular group, rather than of the whole. The pastor in the above example was closed to the activity of the Spirit. He was concerned with efficiency

³⁴⁵ Reinders, "What’s Wrong with Charity? Considerations for a Modern Travesty of Christian Ethics," p. 15.

and a thin gesture of inclusion. He did not believe that the needs of those with physical and developmental disabilities in the congregation should be considered along with the needs of everyone else. He was more concerned about efficiency rather than authenticity. Not only was he not concerned about the people and their needs, it is one of the few situations I have encountered where the practice disregarded liturgical norms. Typically, the resistance claims the need to follow the rubrics of the liturgy. In this situation however, the pastor's solution was to distribute communion while processing out of the sanctuary. In other words, *after* the Liturgy of the Eucharist and *after* the Concluding Rites, so mass was over.

D. Does Charity Have a Future?

The metaphor for monastic charity, the "two faces of Christ," communicates mutuality and reciprocity. Host and guest, comforting and vulnerable, and these roles change as the circumstances warrant. In other words, they are not static. The scriptural passage of Jesus washing Peter's feet has always impacted me and it provides a helpful scriptural illustration of this (Jn 13:3-15). Peter, full of angst recoils, says, "You will never wash my feet" (Jn 13:8). Yet, Jesus is adamant he should allow it.³⁴⁶ Foot washing in Jesus' day was a part of hospitality that was performed by slaves.³⁴⁷ Yet Jesus, their rabbi, is washing their feet. But servant leadership is not the only thing Jesus is teaching them. He is not only teaching the disciples to serve, but to *be served* as well. The connection between vulnerability, service and discipleship is clear. Jason Greig, in "Striving Towards Dependence: An Alternative Mennonite Anthropological Witness in Late Modernity" notes the preponderance of contemporary theological reflection on this scene focused on service, suggesting that it is "much more

³⁴⁶ Ford Madox Brown, "Jesus Washing Peter's Feet," <http://www.victorianweb.org/painting/fmb/paintings/1.html> For a copy of the classic illustration of this text.

³⁴⁷ PHEME PERKINS, "The Gospel According to John," in *The New Jerome Biblical Commentary*, ed. Raymond Edward Brown, Joseph A Fitzmyer, and Roland Edmund Murphy (Upper Saddle River, NJ: Prentice Hall, 1968), p. 973.

comfortable being foot *washers* rather than being the foot *washed*.³⁴⁸ Greig's criticism of developments in the Mennonite Church are no less relevant for the Christian Church at large, which is just as susceptible to the influences of contemporary society.

Truly practicing charity requires openness to be served, as well as to serve and to allow for the possibility of new insights into ways of being Church. Meaning and purpose can be lost when focused on rubric and form. In washing Peter's feet, Jesus was performing the task of a slave, someone without status, power or political position. This was not to be nice. Peter's agony is proof of that. He was teaching Peter to let himself be served, to be willing to defy norms, and to challenge structures. Indeed, "There is no longer Jew or Greek, there is no longer slave or free, there is no longer male and female; for all of you are one in Christ Jesus. And ... you are Abraham's offspring, heirs according to the promise (Gal 3: 28)." Truly practicing charity knows that individuals with IDD can also serve others.

Another consideration in mutuality is a suitable connection between the opportunity for charity and the holy innocent, perpetual child thread of the *shadow narrative*. Patronizing charity wants to take care of people, believing incorrectly that they cannot take care of themselves, just like children. There is another related scripture passage that is often misunderstood. "Let the children come to me; do not prevent them, for the kingdom of God belongs to such as these," (Mk 10:14-15). However, the Aramaic word for servant, *talyā*, was also used for child.³⁴⁹ So Jesus is not talking about sweet, innocent children here. He is talking about individuals who are vulnerable and powerless, who had no legal status in his day. In other words, Jesus is suggesting that when we discover our vulnerability and powerlessness, we will encounter God. The welcome ritual of foot washing in *The Rule of St. Benedict* reflected this as an example

³⁴⁸ Jason Greig, "Striving Towards Dependence," *Anabaptist Witness* (2014): p. 49-50.

³⁴⁹ Daniel J Harrington, S.J., "The Gospel According to Mark," in *The New Jerome Biblical Commentary*, ed. Raymond Edward Brown, Joseph A Fitzmyer, and Roland Edmund Murphy (Upper Saddle River, NJ: Prentice Hall, 1968), p. 616.

of *koinonia*. To follow Jesus is to accept the defiance of norms, to reject the *cult of normalcy*, as he showed us in washing the disciples' feet. We need to identify with those who are vulnerable and poor, because we are vulnerable and poor. Independence is a fallacy, we are all interdependent, even if it is to different degrees. Touching the vulnerable space inside someone who is seemingly powerful is charity as well.

If we honestly engage with the narratives of a person's life, we are called to respectfully enter, opening ourselves to being changed in the process, calling for reciprocity as, "narrators, authors, listeners and readers."³⁵⁰ It allows people to see the person beyond the diagnosis.³⁵¹ Acknowledging the difference between author and narrator within this practice clarifies whose voice is operative.

Carrie Doehring describes connecting with the narratives of a person's life in pastoral care and presence,

The process of stepping respectfully into another's narrative world can be described with the metaphor of hospitality. a more reciprocal way to

³⁵⁰ Herman P Meininger, "Narrating, Writing, Reading: Life Story Work as an Aid to (Self) Advocacy," *British Journal of Learning Disabilities* 34, no. 3 (2006): p. 187. Meininger introduces the role of narrator, rather than author, for contributors to life stories about a person. This is a nice differentiation that helps with the question of authorship of life story work.

³⁵¹ Ibid., pp. 181-188; Amanda Clarke, Elizabeth Jane Hanson, and Helen Ross, "Seeing the Person Behind the Patient: Enhancing the Care of Older People Using a Biographical Approach," *Journal of Clinical Nursing* 12, no. 5 (2003); Gugu Kristoffersen, "Life Story Work: An Important, but Overlooked, Instrument," *Mental retardation* 42, no. 1 (2004); Rachel Thompson, "Using Life Story Work to Enhance Care: Rachel Thompson Describes How Staff Can Be Supported to Implement and Sustain Biographical Approaches with Clients," *Nursing older people* 23, no. 8 (2011). Life Story Work is a process used in gathering illustrations, stories and narratives of a person's life to empower and see beyond the diagnosis have also been shown to facilitate relationships between the service provider, the person receiving services and his/her family, as well as fostering self-awareness and self-advocacy. Though initially used primarily with persons with dementia, there have been many endorsements of applying the same principals to facilitating relationship and nurturing meaningful participation for individuals with I/DD.

describe how the roles of host and guest alternate and all parties are inevitably changed through experiences of hospitality. The mingling of the care seeker's and caregiver's narrative worlds generates an intersubjective space for meaning making.³⁵²

This beautifully recalls the “two faces of Christ.” Learning the narratives of someone's life is not just filling out a form; it is getting to know them in particular, not as part of a diagnostic label. It is to be an encounter, entered into with respect and bringing myself to it as well. I am called to be changed AND to change in the process, and we, the Church, are called to this as well. We are changed, by allowing ourselves to be touched by the other person. We change, by making conscious choices to do things differently to enhance meaningful participation for all. Otherwise, we are simply “making space” in the pews, rather than facilitating true discipleship, relationship and participation.

Reclaiming charity that is based on human dignity would look very different than its corrupted model. Catholic Social Teaching provides this basis, which respects the dignity of every person, who is created in the image of God. Charity, *caritas*, is both its central value and animating force. Locating someone's value in providing others the opportunity to grow in love, or become better people, misses the presence of Christ in them, thus undermining the two faces of Christ that was so integral to monastic charity. To move beyond the subverted practice of charity, Pope Benedict suggests that “truth needs to be sought, found and expressed within the “economy” of charity,”³⁵³ The process of *doing* charity matters. In this way, charity, formed by truth, moves beyond sentimentality and emptiness, it moves beyond outdated stereotypes and prejudices, and finds new solutions as it unites knowledge and practice for human and community flourishing. The ability to do this, which requires the ability to be concerned beyond one's self comes through activity of the Spirit (Rom 5:5).³⁵⁴

³⁵² Carrie Doebling, *The Practice of Pastoral Care: A Postmodern Approach*, (Louisville, KY: Westminster John Knox Press, 2015). Kindle Book. p. xvii.

³⁵³ Pope Benedict XVI, *Caritas in Veritate (Charity in Truth)*. par 2.

³⁵⁴ *Ibid.*, par 3-5, 30-32.

Does charity have a future? This chapter opened with an example of Pope Francis being called to task for saying that individuals with disabilities provided the opportunity to others to grow in love, essentially through their service to their family member with a disability. His text in *Amoris Laetitia*, as I discussed, never noted individuals with disabilities as persons of interest in their own right. However, Pope Francis has demonstrated his openness to the Spirit and his willingness to reevaluate his positions, based on the experiences of people he is talking about. A little over a year after the encyclical was promulgated, he addressed attendees of a conference, “Catechesis and Persons with Disabilities: A Necessary Engagement in the Daily Pastoral Life of the Church.” His message did not focus on suffering, but noted the isolation and marginalization that comes from attitudes and inhospitable structures. He also noted that a girl he met in Columbia helped change his narrative by reminding him that vulnerability is part of being human.³⁵⁵ If one person can change, others can as well and Pope Francis, as pope, is well positioned to influence others.

The Council affirmed the development of doctrine, as has already been discussed, noting this was done by studying “sacred tradition and doctrine of the Church – the treasury out of which the Church continually brings forth new things that are in harmony with the things that are old.”³⁵⁶ In the same Spirit, let us return to sacred tradition and follow the growing end of human dignity. There was a time when individuals with IDD were thought to need taking care of, because they were incapable of learning and development. That time is passed. Therefore, this love of neighbor must respectfully acknowledge our shared humanity with sincere interest in the other, for their benefit, not a self-serving desire for closeness to God. This love of neighbor must

³⁵⁵ Pope Francis, "Address of His Holiness Pope Francis to Participants in the Conference Organized by the Pontifical Council for Promoting New Evangelization," (Vatican Libreria Editrice Vaticana, October 21, 2017).

³⁵⁶ Council Fathers of Vatican II, "Declaration on Religious Freedom (Dignitatis Humanae)," ed. Walter M Abbott, Kindle Edition ed., *The Documents of Vatican II: Introductions and Commentaries by Catholic Bishops and Experts, Responses by Protestant and Orthodox Scholars* (America Press Inc., 1966; repr., April 30, 2012). par 1.

rejoice in the love found by Floris and Renee, rather than bless Floris. How might this be accomplished? In the next chapter we will begin framing our response by first asking a different question.

V. Who Do We Say We Are?

The principles of symbolic interactionism suggest that there is a need for co-sensuality whereby humans help each other unfold and establish contact and unity in their social existence.

~ Trevor Parmenter, "Inclusion and quality of life: Are we there yet?"³⁵⁷

The opening question of this project, "Who do you say that I am?" seeks to understand why individuals with IDD continue to be marginalized within the US Catholic Church. I identified an underlying force, which I named the *shadow narrative* in the second chapter and discussed more fully in chapter 3. The continuing discussion within these pages seeks to understand and expose the source for the *shadow narrative*. Following the trail in search of an answer, the implications of this question have been explored within a context of faith that proclaims the innate dignity of every person who is created in the image of God, utilizing ecclesial documents as to what the US Catholic Church says specifically about individuals with disabilities, in society and within the life of the Church. This reveals a vision that announces the pastoral responsibility of the Church to promote human development and flourishing, which is grounded in Catholic Social Teaching. It provides the framework to live one's faith within the details of daily life, as individuals, collectively as a church and as a political body, the United States, and also for the lived expression of the dual commandment to love God with one's whole heart and to love one's neighbor as oneself. This underpins all the Catholic Church professes.

Yet the Church continues to focus activities 'for' individuals with disabilities with the purpose of 'them' either 'fitting in' within the Church as is, which remains unchanged, or establishing segregated programs that are isolated from the general congregation membership. Such activities are driven by the *shadow narrative* presented earlier, which include five false threads that diminishes the Gospel's light. The narratives follow one of five themes regarding persons with disabilities: opportunities for

³⁵⁷ Trevor R Parmenter, "Inclusion and Quality of Life: Are We There Yet?," *International Public Health Journal* 6, no. 4 (2014).

service and “charity,” forever children, innocent and unable to sin, a special relationship with Jesus and the cross, the slippery slope of idealism, or totally “other.” Flipping the question, for the Church to reflect on who it claims to be, assists in the search to understand why this happens, as well as provides the theological framework for assessment and response. This question is not posed idly, however and the reason to pivot the discussion will be evident shortly. This chapter is the transitional point of my thesis from analysis to understanding and constructive response.

The effect of the *shadow narrative* is not incidental. It is woven through the development of ministry with persons with IDD and ecclesial documents and also found in the words of people who have devoted their lives to advocating for persons with IDD, often quite unexpectedly, such as the writings of Jean Vanier. Vanier was a prominent Roman Catholic voice within conversations at the intersection of theology, disability and pastoral practice throughout his life, and he did much to raise awareness about the abilities and needs of persons with IDD. Vanier, who died in 2019, lived a life that, *on the surface*, was a counter cultural witness to the gospel as the founder and spiritual leader of L’Arche communities. Deeply troubling revelations came to light about abusive relationships he had with some of the assistants at L’Arche. While Vanier is no longer a credible voice regarding this subject, engaging with his words is still viable, because of his influence while alive.³⁵⁸

He has said that we will only find peace and true community when we accept our own vulnerability, and no longer view others based on their ability to serve our own purpose, healing or enhancement. Further, that our communities will be truly nourishing when we are able to choose to become nourishment for others, motivated by the sincere interest in others, as well as recognize that this is the essence of who we are called to be as human beings.³⁵⁹

³⁵⁸ I already discussed problems with writings of Henri Nouwen in *Adam: God’s Beloved*. In this discussion, however, I am responding to particular published statements of Vanier, which is why Nouwen is not part of the discussion.

³⁵⁹ Jean Vanier, *Community and Growth*, Revised ed. (New York: Paulist Press, 1989), pp. 47-60, 330.

However, at times Vanier's language has reflected the undermining *shadow narrative* discussed earlier.

It is often the poorest person – the one who has a handicap or who is ill or old – who is the most prophetic. These people should not be sucked into the structure of the community; that would deflect them from their gift, which is to love and serve or, even more, to call out for love and awaken compassion and service in the hearts of others.³⁶⁰

It is the love of the hidden people which keeps the community united. The leader brings unity through justice, but these loving people are creators of unity just by being who they are. In their tenderness they are artisans of peace.³⁶¹

These two examples represent closely related and resilient threads of the *shadow narrative* I described before. It is a narrative that patronizes individuals with disabilities and perpetuates their dependency and marginalization within the Church. The first example says that the purpose of persons with IDD within community life is to draw out compassion and service in others. The second notes their simplicity and innocence, providing an alternative example of living our humanity to the larger community.

Vanier's language against individuals with IDD becoming involved within community life is strong and defensive, that they should not be "sucked into" its structures, because it would prevent them from being able, "to awaken compassion and service in the hearts of others." Such sentiments do very little, if anything, to overcome segregated programs and activities for individuals with IDD within congregational life. It sidelines them from planning discourse and maintains a single vocation for persons with IDD within the mission of the Church. Nor do such idealized and simplified presentations of persons

³⁶⁰ Ibid., p. 262.

³⁶¹ Ibid., p. 263. Because of Vanier's broad scope of influence, such sentiments make it difficult to change attitudes in the church at large and reinforces continued marginalization. As an example, after listening to a presentation about the relevancy of Aquinas on religious experience in the 21st century, I asked the speaker, Louis Roy, OP, if he had included persons with IDD in his work. "No," he said, Jean Vanier has told me they are "people of the heart." Discussion closed!

with IDD facilitate access to all that is needed to live, “a genuinely human life.”³⁶² Vanier’s words seemingly honor individuals with IDD, but yet he advances a romanticized ideal at their expense.

It brings tensions to the surface about L’Arche that are counter-productive to the way in which it describes its own history, “bringing about 5,000 men and women with a disability into the heart of their societies, making their voice heard, providing a true home and the opportunity to develop their unique gifts to the fullest.”³⁶³ Despite these aspirations, Vanier has also spoken positively about vulnerable persons being sacrificial offerings for the good of the community,

The most precious gift in community is rooted in weakness. It is when we are frail and poor that we need others, that we call them to love and use all of their gifts. At the heart of community are always the people who are insignificant, weak and poor. Those who are ‘useless’, either physically or mentally, those who are ill or dying, enter into the mystery of sacrifice. Through their humiliation and the offering of their suffering, they become sources of life for others. ‘Upon him was the chastisement that made us whole’ (Is 53:5).³⁶⁴

The Christ-like representation of the suffering servant in Isaiah raises a hard question for L’Arche. While I agree that communities are stronger when its members recognize their own vulnerabilities and interdependence, it must also be said that the Church professes that Christ’s sacrifice was for the world. Once given, such sacrifice is not called for again.³⁶⁵ The belief that individuals ‘suffer,’ thus deepening their spirituality

³⁶² Council Fathers of Vatican II, “Pastoral Constitution, Flannery,” par 26. Lists basic needs, food, shelter, healthcare, etc as well as those necessary for development and participation in human community, such as education, employment, political process, etc; USCCB, “A Century of Social Change: A Common Heritage, a Continuing Challenge,” par 17, 64, 77-80; Pontifical Council for Justice and Peace, “Compendium of Social Doctrine,” par 160-191.

³⁶³ L’Arche International, “Who We Are,” L’Arche USA, <https://www.larcheusa.org/who-we-are/larche-international-2/>.

³⁶⁴ Vanier, *Community and Growth*, p. 263.

³⁶⁵ Catholic Church, CCC, 618.

and providing an example to others is very much connected with the thread of the *shadow narrative* that posits a special connection between individuals with IDD, the cross and Jesus. The statement displays a potential for victimizing vulnerable individuals. Although Vanier is referring to socially mediated assessments of value, his words do not expose the practice and purpose. There seems little consistency between the Gospel and the practice of building community life on the humiliation and suffering of vulnerable persons. Rather, these words reveal another strand of the shadow narrative that overly identifies persons with disabilities with Christ and the cross.

Vanier says “the insignificant people” should be asked if a community is faithful to its original vision. Presuming that he is using a culturally mediated description of persons with IDD as ‘insignificant,’ it appears that he is using the description instead of dismantling it. So, even in the work of someone who is considered to have devoted his life to the service of and with persons with IDD, the answer to the initial question of “Who do you say I am?” does not overcome the problem of the *shadow narrative*. Therefore, I suggest a different approach, to flip the question and ask of the Church, “Who do we say that we are?”

The shadow narrative continues to operate with a fundamental difference between persons with and without IDD that operates as a binary divide between ‘them’ and ‘us.’ Flipping the question will provide an opportunity to overcome this division, first, by asking a fundamental question about the Church in its entirety, and second, by unpacking its implications. The Council Fathers at Vatican II proclaimed the Church to be a sacrament of Christ in the world,³⁶⁶ which suggests that the notion of the body of Christ provides potent implications about its nature and purpose.

³⁶⁶ Council Fathers of Vatican II, “Dogmatic Constitution on the Church (Lumen Gentium),” ed. Walter M Abbott, Kindle Edition ed., Kindle vols., *The Documents of Vatican II: Introductions and Commentaries by Catholic Bishops and Experts, Responses by Protestant and Orthodox Scholars* (New York: America Press Inc., 1966; repr., April 30, 2012).

A. We Are the Body of Christ

Paul's letter to the Church in Corinth, particularly 1 Cor 12, is a central text for discussions about the body of Christ, and is a favorite for discussions about the participation of individuals and groups who are marginalized within the Church. According to Catholic reading of the text, Paul is stressing to the Church in Corinth that the body of Christ is made of many members who are each gifted in different ways through the power of the Spirit. Though there are many parts of the body, it is called to be a cohesive unit that is fueled by mutual love in the Spirit, reciprocally experiencing the pain and joy of the other members. Each member contributes to the whole, and those who do not properly participate nor contribute, diminishes the Church and themselves.³⁶⁷

Paul is chastising the community not only for valuing certain manifestations of the Spirit over others, but also for adopting misplaced prideful attitudes about them. This causes divisive practices within the community, which devalues and marginalizes members who do not share in the valued spiritual gifts.³⁶⁸ He offers the analogy of the community as the body of Christ, which consists of many members who all "share a common existence in Christ."³⁶⁹ Through baptism, the members of the Church form an interconnected and interdependent organ, as the body of Christ. Just as a body has many parts, so the body of Christ has many members. Each person makes unique contributions for the common good, though the Spirit is still the source and operator of these gifts. All members are equally valuable and valued, and it is incomplete if any are

³⁶⁷ "Decree on the Apostolate of the Laity (*Apostolicam Actuositatem*)," ed. Walter M Abbott, Kindle Edition ed., Kindle vols. (New York: America Press Inc., 1966; repr., April 30, 2012). pp. 7, 2.

³⁶⁸ Jerome Murphy-O'Connor, "The First Letter to the Corinthians," in *The New Jerome Biblical Commentary*, ed. Raymond Edward Brown, Joseph A Fitzmyer, and Roland Edmund Murphy (Upper Saddle River, NJ: Prentice Hall, 1968), p. 810, section 59.

³⁶⁹ *Ibid.*, p. 810, section 60.

missing.³⁷⁰ Therefore, there is no cause for pride, which many in Corinth are guilty of.³⁷¹

As noted in the earlier chapters, the Church still struggles to live this authentically. Why is that? Perhaps the Church's interpretation of Paul's letter has become disconnected from his intentions when he wrote to the Church in Corinth, just as the practice of charity has become disconnected from its roots, misunderstood and compromised. Professor Brian Brock challenges the typical reading of 1 Corinthians 12 which focus on a finite list of gifts of the Spirit that are gifted to individuals to feed their participation and contributions to the Church. Such positions feed the *shadow narrative* discussed earlier, because it reinforces cultural values of independence, which often leads to the result that the gifts of persons with disabilities are defined by their disability, restricted to other predefined spaces, used as objects of service for others, and/or patronized with minimal expectations. Brock accuses liberal societies in particular of the last one, and particularly challenges patristic exegesis that says the body of Christ depends on vulnerable individuals to provide opportunities for Christ-like service.³⁷²

Brock's analysis contradicts simple and sentimental readings of the text that focus on how individual parts of the body contribute to the whole, because they contradict the message of mutuality that permeates Paul's message, which comes *from* the Spirit *through* the interconnectedness of all within the body, as manifestations *of* the Spirit. Paul is not presenting a listing of individual gifts of the Spirit. Brock makes a compelling argument that they lack the contextual understanding when Paul wrote the letter to the Church in Corinth. I am grateful to Brock for opening this channel to

³⁷⁰ Council Fathers of Vatican II, "Decree on the Ministry and Life of Priests (Presbyterorum Ordinis)," ed. Walter M Abbott, Kindle Edition ed., Kindle vols. (New York: America Press Inc., 1966; repr., April 30, 2012). On p. 6, fn. 82. The Fathers cite an allocution by Pope Paul VI to Italian clergy to teach the importance of coming together and of not staying away. Otherwise the body is incomplete.

³⁷¹ Murphy-O'Connor, "Corinthians, NJBC," p. 810, sections 59-60.

³⁷² Brian Brock, "Theologizing Inclusion: 1 Corinthians 12 and the Politics of the Body of Christ," *Journal of Religion, Disability & Health* 15, no. 4 (2011): p. 369.

challenge scriptural analysis on such a foundational text located at the intersection of disability, theology and pastoral practice. His insights challenge the traditional focus on individual gifts that diminishes, rather than enhances, possibilities for God's activity within the body of Christ, and thus, its possibilities to serve as leaven for the world.³⁷³

Paul cautioned the Corinthians about their fascination with spiritual gifts and to forget their pagan ways (NIV, 1 Cor 12:1-3).³⁷⁴ Those that believed they had these gifts, set themselves apart from others who were not so gifted. Paul had already cautioned them about the importance of love over knowledge (1Cor 8: 1b).³⁷⁵ Knowledge was only helpful if it served a greater purpose, used with love, but it was not an end in itself.³⁷⁶ Gifts are not individual achievements, but considered gifts because they benefited the community at large. Paul believed that, "life in the Spirit required each person to develop responsible, loving relationships in the body of Christ, and their times of public worship must be for mutual edification, not for heightened individualistic spirituality, which in their case, had become a false spirituality."³⁷⁷ Such attitudes still erupt in the Church today. A woman religious complained to the father of a young man with autism that the noise he made during Mass, "robbed her of her spiritual joy." So, understanding Paul's message to the Church in Corinth then, is still important for the Church today.

Every year confirmation candidates learn the gifts of the Spirit as a finite list of seven and are encouraged to consider what gifts they have to share with the Church. These gifts open them to the activity of the Spirit and prepare them for the twelve fruits

³⁷³ Council Fathers of Vatican II, "Pastoral Constitution, Flannery," par 40.

³⁷⁴ Gordon D Fee, *The First Epistle to the Corinthians* (Grand Rapids, MI: Wm. B. Eerdmans Publishing, 1987), p. 774. Unless otherwise noted, scripture is NRSV. Fee works with the Greek NIV text, and sometimes edits its translation based on his interpretation of the Greek text and culture.

³⁷⁵ Ibid., p. 364.

³⁷⁶ Ibid., pp. 364-369.

³⁷⁷ Ibid., pp. 573.

of the Spirit, which fuel and signify a deeper life in the Spirit.³⁷⁸ The Catholic understanding of the body of Christ described above is very rich and has served the Church well for many ways. Yet it has also presented the activities of the Spirit as something which occur within people in “possession of the Spirit,”³⁷⁹ inadvertently reinforcing emphasis on the individual person as agent. This actually reinforces valuing independence and undermining the interdependent nature of the body that Catholic Social Teaching articulates. This then marginalizes individuals who are more visibly vulnerable and dependent. Even when persons with disabilities are valued for the gifts they contribute to the Church, these are very often connected to their disability or marginalized status. Balancing the individual and the common good is a delicate balance that Catholic Social Teaching works at.

Brock’s thesis illustrates the implications of misreading Paul’s text about the body of Christ that has undermined proper valuing and appreciation of persons with IDD as part of the body of Christ. Building on this will also demonstrate how such misinterpretations have fed the *shadow narrative*. Three particular areas of interest surfaced while studying Brock’s work: gifts vs. manifestations of the Spirit, diversity in unity, and identifying the weak members. Although there is general acceptance of Paul’s metaphor of the body of Christ for the Church as an interdependent communion of members, there are some key differences, which have profound implications. I will draw on two additional voices to support and build on Brock’s thesis to address the concerns of this project, Gordon Fee and Jerome Murphy-O’Connor. Anthony Thiselton is one of Brock’s hermeneutical sources, though he only cites him directly once, to provide Greek textual analysis of word for “manifestation” to underscore *charisma* purpose is “for the *common good*.”³⁸⁰ However, he actively argues with Thiselton’s

³⁷⁸ Catholic Church, CCC, par. 1830-1832, 1298, 1299, 1303.

³⁷⁹ Joseph A Fitzmyer, “Pauline Theology,” in *The New Jerome Biblical Commentary*, ed. Raymond Edward Brown, Joseph A Fitzmyer, and Roland Edmund Murphy (Upper Saddle River, NJ: Prentice Hall, 1968).

³⁸⁰ Brock, “Theologizing Inclusion: 1 Corinthians 12 and the Politics of the Body of Christ,” p. 357.

source for patristic theology, John Chrysostom, particularly concerning the 'gift' of individuals with disabilities within Christian community.³⁸¹ Fee maintains that Paul is intent on clarifying that diversity within the body is an ontological reality that supports wholeness, rather than uniformity and order, as Thiselton suggests.³⁸² Murphy-O'Connor brings insights into the architectural and social structures of the day in Corinth that not only aggravate the tensions around attitudes about gifts, but also contributes to the discussion on devaluing and marginalizing vulnerable peoples within the body of Christ.

B. Individual Gifts or Manifestations of the Spirit

Brock makes a compelling case that Paul was focused on the entirety of the body of Christ, within which many manifestations of the Spirit occurred, through the interactive participation of all, or in Brock's words, "the interpersonal dynamics of that body understood as a political entity."³⁸³

4 Now there are varieties of gifts, but the same Spirit; 5 and there are varieties of services, but the same Lord; 6 and there are varieties of activities, but it is the same God who activates all of them in everyone. 7 To each is given the manifestation of the Spirit for the common good.

8 To one is given through the Spirit the utterance of wisdom, and to another the utterance of knowledge according to the same Spirit, 9 to another faith by the same Spirit, to another gifts of healing by the one Spirit, 10 to another the working of miracles, to another prophecy, to another the discernment of spirits, to another various kinds of tongues, to another the interpretation of tongues. 11 All these are activated by one and the same spirit, who allots to each one individually just as the spirit chooses (NRSV).

Neither individual persons nor individual gifts were important, it was the manifestation of the Spirit of God throughout, which people limit by exclusive and

³⁸¹ Ibid., pp. 365, 368-370.

³⁸² Anthony C Thiselton, *The First Epistle to the Corinthians: A Commentary on the Greek Text* (Grand Rapids, MI, Cambridge, U.K.; Carlisle, Cumbria: Wm. B. Eerdmans Publishing; The Paternoster Press, 2000), pp. 1021-1023.

³⁸³ Brock, "Theologizing Inclusion: 1 Corinthians 12 and the Politics of the Body of Christ."

marginalizing practices.³⁸⁴ Brock chastises such self-referential questions as, “what is my gift,” because they are contrary to God’s way and undermine openness to the activity of the Spirit. The better question, he says is, “how do I embrace the giving of the Spirit?”³⁸⁵ Emphasizing individual gifts focuses attention on individual contributions, rather than the interdependent nature of the body, which becomes something new and more than the sum of parts in Christ. The Church in Corinth was guilty of this in Paul’s day, and the Church today is as well. Brock challenges the Church today to study the text more closely for potent possibilities to reimagine what it means to be the body of Christ, particularly for individuals from marginalized groups, such as persons with IDD.³⁸⁶

The manifestations of the Spirit become evident through the interactions between members. Brock says,

If every member of the body is not merely a possessor of a portion of the respective gift allotted to him or her in the respective charisma, but is rather a revealer of the Spirit to the body as a whole, then there cannot be a central agency that administers the Spirit, arranging and rearranging the spiritual body. The Spirit alone is the arranger of the gifts that make up the different parts of the body.³⁸⁷

In other words, the gift is revealed in the discovery and embracing that happens between members, but the activity comes from God, for the common good. Also, there is no central authority operating within the body organizing this, only God’s Spirit moving where it will. A manifestation makes something that is hidden perceptible.³⁸⁸ Another word for manifestation is materialization. This could be a process of something coming

³⁸⁴ Ibid.

³⁸⁵ Ibid., p. 365.

³⁸⁶ Ibid.

³⁸⁷ Ibid., pp. 357-359.

³⁸⁸ "s.v. "Manifestation,"" in *Merriam Webster.com Dictionary* (Springfield, MA: Merriam-Webster, Inc).<https://www.merriam-webster.com/dictionary/manifestation>.

into existence through the natural world, rather than through human activity,³⁸⁹ or a phenomenon brought about by another phenomenon.³⁹⁰ It could also be something perceptible that validates or reveals the presence of something else, such as a divine essence.³⁹¹ Other words for materialization are incarnation and embodiment, which are particularly relevant. Discernment within such a body will be important and something to consider during this discussion.

It is possible to say then, the gifts that become present through the engaged spaces between members of the body are embodiments of God's Spirit, or its incarnation. In other words, the manifestations of the Spirit happen within relationships, yet it is important that these relationships be animated by charity, as discussed in the last chapter. Such would prevent the patronizing and marginalizing attitudes alive in the Church today. This is consistent with Fee, who insists that Paul is focused on the Spirit and the body as a whole, and the expansive possibilities of God who works all of them in all people, as embodiments of the Spirit. The different kinds of gifts, service and work, are all from the same Spirit, the same Lord, the same God. (1 Cor 12:4-11). Contrary to a finite list of gifts, the possibilities for the embodiment of God's Spirit in the Church are limitless when members come together as an interdependent communion. Paul's analogy of the body of Christ to the human body portrays an interdependent communion of members which reincarnates the Spirit in its midst. Tending to the common good lifts up the body, and all are enhanced, whereas focusing on individual giftedness points away from Christ and restricts the incarnation of the Spirit.³⁹² As noted before, the dance balancing tensions between individual and the whole is not easy, but one which

³⁸⁹ "s.v. Materialization," in *American Heritage Dictionary of the English Language, Fifth Edition* (Houghton Mifflin Harcourt Publishing Company).<https://www.thefreedictionary.com/materialization> .

³⁹⁰ "s.v. Materialization," in *WordNet* (Princeton University, 2010).Found on <https://thefreedictionary.com>

³⁹¹ "s.v. Materialization," in *The American Heritage Roget's Thesaurus*.<https://www.thefreedictionary.com/materialization>

³⁹² Fee, *The First Epistle to the Corinthians*, pp. 582-589, p. 602.p. 602, fn 12

Catholic Social Teaching seeks to address. However, the next section will provide some more clarification.

C. The Body of Christ: Unity in Diversity or Diversity in Unity?

Fee insists that Paul is intent on clarifying that diversity within the body is an ontological reality that supports wholeness. Although Brock does not focus on the need for diversity, he calls the Church to remain open to new and unexpected incarnate possibilities of the Spirit from intersectional spaces of encounter between all within the body, regardless of their status in the world.³⁹³ Fee's work enhances Brock's challenge to the Church for all to be equally valued, regardless of position in society, abilities, disabilities, or any other categories. While Fee does not suggest a decentralized communion that Brock notes in his analogy to the human nervous system, he does not rule out such open interaction.

Rather, he points out that Paul addresses the need for some order within the community at worship, if it is to edify Christ. However, he strongly opposes suggestions that Paul is focused on uniformity and order,³⁹⁴ which is Thiselton's perspective on the text. Thiselton strenuously criticizes Fee's position a number of times.³⁹⁵ Upon further inspection, it is evident that Fee has something to contribute to the discussion. The contention between the two positions, brings two counter models of ecclesiology into sharp relief. It is a tension that persists to this day, as evidenced by the extent of Thiselton's complaints about Fee's position. Is the body of Christ an interdependent communion of persons, ever open to new embodiments of God within it, as well as its activity in the world? Or is it an ordered entity, within which uniformity must be maintained according to a particular order?

³⁹³ Brock, "Theologizing Inclusion: 1 Corinthians 12 and the Politics of the Body of Christ," p. 372.

³⁹⁴ Thiselton, *The First Epistle to the Corinthians: A Commentary on the Greek Text*, pp. 990-993, 1021-1023.

³⁹⁵ Ibid. p. 1023

Greco-Roman analogies of political society to the human body were well known in Paul's day, and it is generally accepted that Paul and the Corinthians were familiar with them.³⁹⁶ Brock shares the fable of Menenius Agrippa, a Roman senator, when facing a rebellious crowd, as the likely inspiration of Paul's message to the community.

In the days when man's members did not all agree among themselves, as is now the case, but had each its own ideas and a voice of its own, the other parts thought it unfair that they should have the worry and the trouble and the labor of providing everything for the belly, while the belly remained quietly in their midst with nothing to do but to enjoy the good things which they bestowed upon it. They therefore conspired together that the hands should carry no food to the mouth, nor the mouth accept anything that was given it, nor the teeth grind up what they received. While they sought in this angry spirit to starve the belly into submission, the members themselves and the whole body were reduced to the utmost weakness. Hence it became clear that even the belly had no idle task to perform, and was no more nourished than it nourished the rest, by giving out to all parts of the body that by which we live and thrive, when it has been divided equally amongst the veins and is enriched with digested food—that is, the blood. Drawing on a parallel from this to show how like was the internal dissension of the bodily members to the anger of the plebs against the Fathers, he [Menenius Agrippa] prevailed upon the minds of the hearers.³⁹⁷

The above text portends what happens when the different parts of the body conspire against the belly, who they felt contributed nothing to its overall condition, yet benefited from all their labor. This resulted in the other members of the body realizing that the apparent freeloader was in fact providing its own important contribution to its overall well-being, thus reinforcing the interdependence of its members. Paul began with a familiar metaphor for a political entity, which he then turns on its head pointing to the Church's *difference* from other political entities, says Brock, it's relatively "unnatural nature."³⁹⁸ Rather than the nature of political bodies, the body of Christ reflects the

³⁹⁶Fee, *The First Epistle to the Corinthians*, p. 602, fn.12; Fitzmyer, "Pauline Theology," par. 122, p. 1409; Thiselton, *The First Epistle to the Corinthians: A Commentary on the Greek Text*, pp. 989-994, 995.

³⁹⁷Brock, "Theologizing Inclusion: 1 Corinthians 12 and the Politics of the Body of Christ," p. 361. Brock quotes from Livy, *Historia*, (2.32.9-12).

³⁹⁸Ibid., p. 362.

covenantal nature of Israel. Also, it is a decentralized body that has, “direct sympathetic communication between all the members.”³⁹⁹ Brock compares communication within the body of Christ with the human body’s nervous system, a series of electric pulses sent and received between nerve cells within a decentralized body, instead of the hierarchical digestive system Agrippa used in his analogy. Each member should attend to embracing the giving of the Spirit, and not wondering which gift is theirs. Authentic indication of the Spirit’s presence and activity is revealed, “where the public manifestation serves the common advantage of others, and not merely self-affirmation, self-fulfillment, or individual status.”⁴⁰⁰ Any manifestations that evolve, Brock notes, evolve through the activity of the Spirit, in the spaces, “in between” the members of the body.⁴⁰¹

Following a similar line of thinking, Fee says Paul’s message to the Corinthians concerns a plethora of ways God’s activity is made known by the one Spirit, for the benefit of the common good in 12:8-11.⁴⁰²

12 The body is a unit, yet it is made up of many parts; and although all its parts are many, they form one body. So it is with Christ. 13 For indeed we were all baptized by one Spirit into one body – whether Jews or Greeks, slave or free – and we were all given one Spirit to drink. 14 For indeed the body is not made up of one part but of many.⁴⁰³ NIV

This shared experience in the Spirit is their starting point, and what differentiates the Church from a typical political body.⁴⁰⁴ Through this they become one body, which

³⁹⁹ Ibid., p. 363.

⁴⁰⁰ Ibid., p. 357. Thiselton, *The First Epistle to the Corinthians: A Commentary on the Greek Text*, p. 936.

⁴⁰¹ Brock, "Theologizing Inclusion: 1 Corinthians 12 and the Politics of the Body of Christ," pp. 357-359.

⁴⁰² Fee, *The First Epistle to the Corinthians*, pp. 582-589.

⁴⁰³ Ibid.

⁴⁰⁴ Ibid., p. 599.

consists of many interdependent members, who do not lose their uniqueness, yet the old labels have lost their distinctions of status.⁴⁰⁵ The Church in Corinth consisted of people with privileged status and wealth, as well as people without such status, who were laborers or servants. Yet, within the body of Christ, such distinctions went away. This opens up the possibilities for grace amidst all, in and through each person.

But there is another shared experience Paul is referring to as well, sharing in the one bread. At this point it is helpful to recall what Paul says just before this section, when he addresses how they gather as a church. In 11:17-34 Paul sternly addresses their divisive practices as not only the antithesis of how gathering as a church should be done, it denies its validity and warns that they bring judgement on themselves! His comments are directed at the wealthy members of the Church.⁴⁰⁶ Although the Gospel erases implications of class and status distinctions, the Church in Corinth, a Roman colony, was still influenced by its environment, the Roman culture and practices, as well as its architecture. Jerome Murphy-O'Connor provides instructive cultural context for Paul's concerns. Murphy-O'Connor's admits they are hypothetical, but they are based on his archeological studies of Corinth, and are enlightening.⁴⁰⁷

Because so little is known about Greek Jews during the time of Paul, Murphy-O'Connor draws from what was known of the Diaspora. He says that Jews were not full citizens, but did have the right to worship, and there is evidence of synagogues in Corinth (Acts 18: 4,7). However, Christian Judaism was not an officially recognized religion, necessitating gathering for liturgy in people's homes. Yet, Jewish Christians still attended the synagogue, so the Eucharistic gatherings took place sometime afterward in the homes of wealthier individuals. Space, floorplan and social class would shape the dynamics of the Lord's Supper.

⁴⁰⁵ Ibid., pp. 606-607.

⁴⁰⁶ Ibid., pp. 534-568.

⁴⁰⁷ Jerome Murphy-O'Connor, *St. Paul's Corinth: Texts and Archaeology*, Third Revised and Expanded Edition ed. (Collegeville, MN: Liturgical Press, 2002), pp. 6-8, 78-81, 177, 185.

Based on what is known about architecture at that time, Murphy-O'Connor suggests the house churches would use two of the rooms to gather, the dining room (*triclinium*), about 398 square feet, and the atrium (*impluvium*), about 797 square feet. The dining room would have couches along the walls for people to recline and most likely not hold more than 9 people. People would need to sit, rather than recline, in the atrium and it would hold no more than 50 people, though Murphy-O'Connor estimates that effective maximum capacity was between 30 and 40.⁴⁰⁸ Two other factors would also influence dynamics and explain Paul's comments. Seating would be expected to be based on socioeconomic status, so the wealthier individuals would be in the dining room and the remainder, the lower-class people, would be in the atrium, which was not fully protected from the weather. Following Roman hospitality customs, different quality of food and wine was served to guests, based on their status. Not only that, but the food would be carried to the dining room through the atrium, so the guests there would be very aware of the discrepancies. Because the host and wealthier guests were part of the leisure class, they would begin earlier than the others, Murphy-O'Connor posits. As servants or laborers, the others did not have control over their time.⁴⁰⁹

Against this backdrop, Paul's admonitions have new meaning.

In the following directives I have no praise for you, for your meetings do more harm than good. ... I hear that when you come together as a church, there are divisions among you ... When you come together, it is not the Lord's supper you eat, for as you eat, each of you goes ahead with his own supper. One remains hungry, another gets drunk. Don't you have homes to eat and drink in? Or do you despise the church of God and humiliate those who have nothing? ... Therefore, whoever eats the bread or drinks the cup of the Lord in an unworthy manner will be guilty of sinning against the body and blood of the Lord. ... For anyone who eats and drinks without recognizing the body eats and drinks judgement on himself. ... So then, my [sisters and] brothers, when you come together to eat, wait for each other. If anyone is hungry, [you]

⁴⁰⁸ Ibid., pp. 178-182. See Appendix for diagram.

⁴⁰⁹ Ibid. pp. 177-185

should eat at home, so that when you meet together it may not result in judgment. (NIV, 1 Cor 11:17, 18, 20-22, 27, 29, 33, 34)⁴¹⁰

This would essentially be like the wealthy members of a congregation having a meal within the sanctuary before liturgy, with priority seating. Depending on how long the pre liturgy meal lasted and how much wine was consumed, one can only wonder what voices of the Spirit were heard. No wonder Paul would tell them to wait for the others to gather before beginning to eat, as well as to eat at home before they gathered for eucharist, Paul's denials of its existence notwithstanding.⁴¹¹ One can also understand the resentment felt by those who were excluded with such dismissive attitudes and marginalizing practices.

Returning to verses 12-14, Fee insists that Paul's essential point is to reinforce the very nature of God is diversity and unity, and that diversity is the source of the various embodiments of the Spirit for the common good, which they need to be a healthy church. Diversity within unity means a diversity of gifts from and in the one Spirit. However, while Paul is concerned with unity, it requires *diversity*, not *uniformity*, in other words, "diversity within unity."⁴¹² The same Spirit, and overall common good, is differently manifested in the varied gifts. Though the gifts do differ, they cannot be measured in society's terms and values. Thiselton, on the other hand, strenuously argues that here Paul emphasizes the new unified identity in Christ, one Spirit. Diversity either refers to the transcendence of previous categories, such as Jew, Gentile, free person or slave, or to the diversity required for a healthy body. Additionally, the one

⁴¹⁰ Fee, *The First Epistle to the Corinthians*, pp. 534-535, 558, 567. Edited for gender inclusive language.

⁴¹¹ Murphy-O'Connor, *St. Paul's Corinth: Texts and Archaeology*, p. 185; Fee, *The First Epistle to the Corinthians*, pp. 531-569.

⁴¹² *The First Epistle to the Corinthians*, p. 608. For more of Fee's in depth textual analysis of the Greek text and Paul's rhetorical style, see pp. 602-607, particularly scripture fn.13 on p. 602. One other note, Fee believes Paul's reference to the Spirit here refers to their conversion experiences. Others, including Thiselton, insists this refers to Baptism. Though not germane to our discussion, I thought it worth noting.

body can only function as a unit, if “the many perform their assigned functions, however diverse.”⁴¹³

¹⁵ If the foot should say, “Because I am not a hand, I do not belong to the body,” it would not for that reason cease to be part of the body. ¹⁶ And if the ear should say, “Because I am not an eye, I do not belong to the body,” it would not for that reason cease to be part of the body. ¹⁷ If the whole body were an eye, where would the sense of hearing be? If the whole body were an ear, where would the sense of smell be? ¹⁸ But in fact God has arranged the parts in the body, every one of them, just as he wanted them to be. ¹⁹ If they were all one part, where would the body be? ²⁰ As it is, there are many parts, but one body.

The implications of living as the body of Christ requires respecting that there is no priority of persons, just as there is no priority of gifts. Paul is concerned about the social prejudices that are dividing the community and harming the body of Christ in Corinth.⁴¹⁴ Neither individual gifts nor individual members could be judged as lesser than another, it was the embodiment of the Spirit of God active throughout that is important, and which the Church limits by exclusive and marginalizing practices.

This is an important consideration to understand Paul’s meaning and intention. Thiselton misses Fee’s point when he continuously argues against Fee’s emphasis on diversity, and his argument is not convincing: “Yet again Fee’s repeated comment that Paul’s “concern throughout has been the need for diversity” conflicts with much of our argument and detailed research and exegesis.”⁴¹⁵ They both say Paul is concerned with the unity of the whole, and affirm the integrated and interdependent whole of the body of Christ, but their understanding of unity is different.

⁴¹³ Thiselton, *The First Epistle to the Corinthians: A Commentary on the Greek Text*, pp. 990-1002.

⁴¹⁴ Fee, *The First Epistle to the Corinthians*, pp. 608-611.

⁴¹⁵ Thiselton, *The First Epistle to the Corinthians: A Commentary on the Greek Text*, p. 1023.

Thiselton's "unity within diversity" is more concerned with order, uniformity and hierarchy, while still acknowledging equal value of all members.⁴¹⁶ Not that Fee diminishes the need for order, it is needed to the extent that nothing is detracted from the liturgy. It is just not an ontological issue. That is the key difference. Fee says that the unity of the body *depends* on diversity of different members, otherwise it is a monstrosity. So for Fee, diversity is an ontological issue.⁴¹⁷ Fee's arguments makes sense, and there is additional support to counter Thiselton. There was little interest beyond simple church structure that was inconsistently implemented before 65 C.E.. Those concerns began to gain traction in the post-apostolic age, 65-100 C.E.⁴¹⁸ Additionally, the Catholic Church notes that unity is the essence of the Church, yet a wide variety of persons and cultures form a communion. Diversity is valued and respected, though it all serves the whole, and charity is the bond to hold it together.⁴¹⁹

D. Who are the "Weak"

²¹ The eye cannot say to the hand, "I don't need you!" And the head cannot say to the feet, "I don't need you!" ²² On the contrary, those parts of the body that seem to be weaker are indispensable, ²³ and the parts that we think are less honorable we treat with special honor. And the parts that are unpresentable are treated with special modesty, ²⁴ while our presentable parts need no special treatment. But God has combined the members of the body and has given greatest honor to the parts that lacked it, ²⁵ so that there should be no division in the body, but that its parts should have equal concern for each other. ²⁶ If one part suffers, every part suffers with it; if one part is honored, every part rejoices with it.

Who does Paul consider to be the weak members of the body? Brock notes different perspectives on who are considered the weak members of the body within

⁴¹⁶ Ibid., pp. 990-994. Commenting on 1 Cor 12: 29-30.

⁴¹⁷ Fee, *The First Epistle to the Corinthians*, pp. 606-607.

⁴¹⁸ Raymond E Brown, Carolyn Osiek, and PHEME Perkins, "Early Church," in *The New Jerome Biblical Commentary*, ed. Raymond Edward Brown, Joseph A Fitzmyer, and Roland Edmund Murphy (Upper Saddle River, NJ: Prentice Hall, 1968), par 27, pp. 1344-1345, par. 33, p. 1346. Brown wrote this portion of the article.

⁴¹⁹ Catholic Church, CCC, par. 791, 813-815.

conversations around theology and disability. He challenges the narratives, what I have named the *shadow narrative*, that locate someone's gift only within their disability, or in other predefined spaces, such as persons with disabilities to be used as objects of service for others, or treated with minimal expectations. Brock believes that Paul is reflecting Jesus's subversive attitudes toward social norms.⁴²⁰

Citing John Chrysostom, who Thiselton refers to on this subject, Brock challenges patristic exegesis that says the body of Christ depends on vulnerable individuals to provide opportunities for Christ-like service. Thiselton engages patristic thought that says, "It is much more the case that those ... less endowed with power or status ... are essential,"⁴²¹ In fact, vulnerable individuals who need care, protection, support and love are needed so that 'believers' may, "serve as Christ served others."⁴²² Quoting Chrysostom, "... The greater have need of the less"⁴²³ Confirming findings in the earlier discussion about charity, Thiselton also cites a more recent voice who supports this use of persons with disabilities for instrumental purposes. According to Thiselton, Jurgen Moltmann suggests that individuals with disabilities are "a 'gift of the Spirit' to the Church through their offering of weakness."⁴²⁴ However, Thiselton oversimplifies Moltmann's position and does not take his larger perspective of gifts of the Spirit into account.

Whatever people are and bring with them is turned into a charisma through the divine calling, because it is accepted by the Spirit and put at the service of God's kingdom. A Christian Jew should remain a Jew and live according to the Torah. A Christian Gentile brings his Gentile culture into the community.

⁴²⁰ Brock, "Theologizing Inclusion: 1 Corinthians 12 and the Politics of the Body of Christ," pp. 367-368.

⁴²¹ Thiselton, *The First Epistle to the Corinthians: A Commentary on the Greek Text*, p. 1007.

⁴²² Ibid., p. 1008.

⁴²³ Ibid., p.1008. Fn 76, Chrysostom, 1 Cor Hom., 31:1,2.

⁴²⁴ Ibid., p. 1009.

Being a woman is a charisma, which must not be surrendered in favour of male ways of thinking and behaving.⁴²⁵

The above quote makes it clear that specificity is important to Moltmann. Also, his perspective on individuals with disabilities is much more nuanced than Thiselton indicates. Moltmann learned first-hand the possibilities individuals with disabilities are capable of, as well as how limiting society effects can have on their lives, through having a brother who had a profound disability.

In *Spirit of Life*, Moltmann refers to patristic tradition regarding people who are strong, weak or have disabilities and acknowledges that the label, “disabled” is conscripted by what Reynolds calls the *cult of normalcy*. Further, their disability is more than the particular disability, it also includes the disabling aspects of society that “robbed [them] of their independence, not just when they are pushed out of public life, but also through the solicitude and protective care they are given in homes.”⁴²⁶ Other people, without disabilities, are responsible for the real harm done and also have the ability, even responsibility, to change this by *seeing the person*, rather than the disability. When we get past the *cult of normalcy*, “we discover the value and dignity of a disabled person and notice its importance for our life together.”⁴²⁷ Unless this is a poor translation, the “it” Moltmann refers to is the disability, not the person who has the disability, that is significant in the lives of other people.

What could Moltmann mean by this? A clue may be earlier in the section on “The awakening of new energies for living.” He says, “It is only when we go out of ourselves that we arrive at ourselves. It is only when try to get beyond our limitations that we discover what they are, and accept them.” This is similar to what I said in the last chapter on charity, about the effect of being in a relationship with someone who is objectively vulnerable, by being drawn out of oneself, one’s self is found. Similarly,

⁴²⁵ Moltmann, *The Spirit of Life: A Universal Affirmation*, 67-68.

⁴²⁶ *Ibid.*, 67.

⁴²⁷ *Ibid.*

Moltmann defines healing within the Gospel, which can offer further clarification. Disrupted social relationships are healed and fellowship with God is restored.⁴²⁸

As I understand Moltmann, he says that *charisma* is based in the particularity of the person, and this particularity facilitates growth in the Spirit of the Christian community through sincere relationships, meaning based on respecting the dignity of each other. Yet, this particularity is based on the person. He notes the specificity of gender, race, ability, and disability, but any one person is a combination of these demographic categories. I'm not sure that Moltmann would disavow the possibility that other *charismata* could evolve through a person's lifespan. After all, when there is growth in the Spirit, "We live and breathe in God's atmosphere. So, the Holy Spirit becomes the new life's vibrating and vitalizing field of energy: we are in God and God is in us."⁴²⁹ Remembering the work of Cahalan and Miller-McLemore, individual vocations are variable and ever-evolving through the call of and response to God within the relationships in our lives.

Returning to the Pauline text, Thiselton's summary interpretation of this suggests that, "All this constitutes a 'beauty of holiness' which is Christlike in its self-effacing being 'for others.' However, the status seekers at Corinth within the Church perceive such humility as 'less presentable' and even an embarrassment, while the gifted ones (socially, spiritually, or in self-confidence of disposition) perceive themselves as the 'essential' core of the Church, says Thiselton."⁴³⁰ While Thiselton correctly notes that Paul is chastising their self-referencing behavior, and thus undermining the essence of what the body is supposed to be, his foundation is what I have hopefully demonstrated is a flawed understanding of Moltmann's position. Thiselton's argument makes even less sense when considering what Paul said in 12:17-34. If Thiselton was correct, Paul

⁴²⁸ Ibid., 66.

⁴²⁹ Ibid.

⁴³⁰ Thiselton, *The First Epistle to the Corinthians: A Commentary on the Greek Text*, p. 1009.

would present those in the atrium who ran out of food and were hungry as opportunities for the wealthy members to be Christ-like. Also, Thiselton uses patristic sources to interpret Paul's sense of the text. While it is interesting from an historical perspective, its exegetical value is limited because of its cultural framework and preference for Greco-Roman rather than Jewish experience.

Fee insists that 'weaker members' is pure analogy, not allegory, and therefore does not refer to individuals of vulnerable groups, such as persons with disabilities, immigrants, or elderly persons. Following the analogy of the body, the weaker parts of the body are internal organs, which one cannot live without, according to Fee. Take out someone's lungs or heart, and the body will die, yet they are hidden, so as to be protected, yet are integral to life. All members are integrally important to the body, regardless of ability, disability, gender, culture, etc. Though Brock denies Paul is talking about internal organs here, Fee's analysis would support Brock's conclusions more effectively. Brock's own analysis of this seems to be overly complicated, reading into the text, and making assumptions about Paul's Jewish/Roman roots.⁴³¹ To summarize Fee's position about Paul's reference to 'weak members,' he is simply reinforcing that the diversity of members, within the unity of the body, is integral to the body of Christ. All are equally valued and equally important, though different.

Next, I will suggest that these interpretations of Paul's intentions, manifestations of the Spirit over individual gifts, diversity in unity, and clarifying who are the weak members, brings a new understanding of the body of Christ that emphasizes its interdependent nature. Such a message is more consistent with the principles of Catholic Social Teaching.

E. Manifestations, Diversity, Weakness: Interdependence

All members of the body of Christ are equally valuable and interdependent within the body fully, such that pain and joy are shared. Noting the problems with importing

⁴³¹ Brock, "Theologizing Inclusion: 1 Corinthians 12 and the Politics of the Body of Christ," pp. 360-362.

normalizing social norms from society into the Church as a defining way of interpreting 'gifts' and the value of persons, Paul warns them that appearances can be deceiving, and social status is a divisive force within the Church.⁴³² Reflecting on this close identification of feelings between the members of the body, particularly considering Paul's priority for love, seems like an excellent example of authentic charity, loving my neighbor as myself. This last expression focuses on diversity as the characteristic that is common across individuals, and thus what unites us. In fact, in the final paragraph Paul reiterates the relationship of diversity within unity, "Now you are the body of Christ, and each one of you is a part of it. ..." and he promises, "[to] show you the most excellent way (12: 27, 31)." This most excellent way is love. But as a "way," love provides context for the manifestations of the Spirit, it is not a gift in itself. Love is the foundation of all, and it is necessary for the building up of the body.⁴³³ All members of the body are equally valued, yet diverse, open to each other in the work of the Spirit, within a body defined by such sympathetic openness of all its members to each other, sharing in the joy and suffering of any one member (24-26).⁴³⁴

Christians belong to the body of Christ, not the other way around. From a Catholic perspective, each and every person belongs by virtue of baptism and the shared vocation is to reflect the image of God, who is love, into the world, individually and communally.⁴³⁵ Even without baptism, there is a shared value that every person is created in the image of God, and therefore precious. There is always a tension in balancing the individual and the whole that is to be discerned through values of the body of Christ. Each of the varied and unique members of the body are important to the whole and the body is incomplete without any one of them (1 Cor 12:12-26). If one part suffers, all suffer and if one part is honored, all share in the joy. The needs of each

⁴³² Fee, *The First Epistle to the Corinthians*, pp. 612-616.

⁴³³ Ibid., p. 625. See pp. 625-652 for further discussion on this.

⁴³⁴ Brock, "Theologizing Inclusion: 1 Corinthians 12 and the Politics of the Body of Christ," pp. 365, 371.

⁴³⁵ Catholic Church, CCC, 1877. Language adapted.

member are a concern for all within what is essentially a communion of brothers and sisters in Christ. The call to live as the body of Christ includes responsibility and expectations for all within it, because everyone is valued and respected, each in their distinctness and difference.

Incorporating principles from earlier chapters can help navigate these tensions. Recall the principle of respect for human dignity, with all that entails, which is the foundation for Catholic Social Teaching, that should be formed within a renewed understanding of charity. Utilizing its three organizational principles of solidarity, concern for the common good and subsidiarity helps navigate the course. Solidarity reinforces the need to feel the experiences of others as one's own (1 Cor 12:26). Concern for the common good considers the needs of the most vulnerable as part of the community's well-being. Such concern counters liberal society's singular focus on individualism and individual rights.⁴³⁶ Subsidiarity means to empower growth and development through participation, rather than dependency. The move beyond dependency that Catholic Social Teaching promotes acknowledges the interdependent and social nature of all human beings, rather than staunch individualism and independence of liberal society. The fallacy of that is becoming ever clearer to more people in light of the current covid-19 pandemic.

Is "diversity within unity" or "unity within diversity" a correct understanding of the body? Fee provides a richer understanding of possibilities for living as the body of Christ, valuing diversity within unity, as a requirement for a body, or a community, to be wholesome. It also provides another dimension to insights brought out in conversations at the intersection of disability and theology. Diversity is the characteristic that is common across individuals, and thus the characteristic that unites us.⁴³⁷ Thiselton's

⁴³⁶ Michael J. Himes, SJ and Kenneth R. OFM Himes, *Fullness of Faith: The Public Significance of Theology* (Mahwah, NJ: Paulist Press, 1993), pp. 63-73.

⁴³⁷ Carlos Thompson, "From Longing to Belonging: Theological Education," in *Summer Institute on Theology and Disability 2019: From Longing to Belonging* (Hope College, Holland MI2019). Acknowledging that communities tend to focus on what characteristics are shared, Thompson suggests that if we were to recognize that, "what

voice detracts, rather than enhances, respect for persons with disabilities within the body of Christ. His argument utilizes the perspective of vulnerable people chronicled in the “opportunity for charity thread” of the *shadow narrative*. This plus his adamant argument for unity that disrespects diversity contradicts the principles of Catholic Social Teaching which says that “the common good depends on a healthy social pluralism.”⁴³⁸ So, his argument is not particularly convincing.

Reynolds, a jazz musician as well as a theologian, provides a provocative metaphor for the body of Christ and manifestations of the Spirit. Reynolds says that through our acknowledged vulnerable interdependence, we open ourselves to each other, which promotes growth, flourishing and community. It is this acceptance of our vulnerability and openness to an inclusive communion that makes each person whole. As the Spirit manifests itself in the spaces in between people, like musicians in a jazz band, they are each different, though important. In the interplay of notes on a sheet of paper, in the call and response amongst and between the musicians, jazz happens, bringing forth something new!⁴³⁹ More than merely an analogy for sympathetic communication with each other, as Brock’s use of the nervous system suggests, jazz provides an image for the creative and lifegiving essence of the embodiment of the Spirit that does what it will. Underlying all of this, Paul says that love is the phenomenon animating the Spirit in the body of Christ.⁴⁴⁰

This chapter transitions the focus of attention from persons with disabilities to who the Church claims to be. It provides the foundation for my constructive argument which responds to the question for the community: how can the Catholic Church create

is uncommon between us is what we have in common,” perhaps community could become a place where difference is held up and celebrated.

⁴³⁸ Pontifical Council for Justice and Peace, “Compendium of Social Doctrine,” par 151.

⁴³⁹ Thomas E Reynolds, “Improvising Together: Christian Solidarity and Hospitality as Jazz Performance,” *Journal of Ecumenical Studies* 43, no. 1 (2008): pp. 39-43, 47-50.

⁴⁴⁰ Fee, *The First Epistle to the Corinthians*, p. 64. Fee on 1 Cor 13:8 – 13.

the kind of space, where persons with disabilities can find their own role? In other words, how can the Church nurture spaces where they can feel comfortable and safe to unfold and discover possibilities, rather than fitting into specific spaces? Paul's admonishments about devaluing and marginalizing practices when gathered as church based on arbitrary characteristics, rather than the Gospel, speak to the Church today, as much as the Church in Corinth. It is not the architecture that forces the divisions and segregations so much today. Today the walls are more often due to attitudes or conflicts between what the Church thinks should be focused on and the perceived "orders of protocol," verses what it thinks persons with IDD can understand or contribute.

The vision of the Church identified, to live as the body of Christ, is undermined by the experiences of persons with IDD feeling marginalized within the Church. Remembering Vanier's question to people who are marginalized in the Church, and having identified the vision the Church proclaims, I will next address the question for the community: how can it nurture a culture where persons with disabilities and other marginalized individuals can develop a sense of belonging and feel comfortable and safe to unfold and discover possibilities, rather than fitting into specific spaces? The answer will necessitate three things: trusting in the presence of the Spirit to animate this process to continually work toward increased comfort and openness with unfolding possibilities, rather than reinforcing what is familiar and therefore more comfortable; recognizing need for change in the Church, rather than making adjustments to persons with disabilities so they can fit in; and attending to the tensions between individuals and the whole, yet respecting all. Social Role Valorization will serve as the corrective tool to understand the nature and dynamics of the *shadow narrative* that will facilitate changing assumptions and questions asked about persons with disabilities, as well as provide a framework for my constructive response. Another question to consider, "What could motivate the Church to make such change possible?"

VI. Exposing the *Shadow Narrative* with Social Role Valorization

“To live factionless is not just to live in poverty and discomfort; it is to live divorced from society, separated from the most important thing in life: community.”

~ Tris, *Divergent*, Book 1 of *Divergent Trilogy* by Veronica Roth

It may help to pause a moment and recap our discussion to this point. The first chapter introduces the problem to be addressed, the rupture between theological statements and pastoral practices regarding individuals with IDD in the US Catholic Church. Groundwork for further conversation was framed by the important parameters of Tradition, the synergy between it, liturgy and pastoral practice, the principles of Catholic Social Teaching, and the influences of models and language as related to mindsets about disability and individuals with disabilities. The last point, models and language, is important to consider the question I seek to address, “Who do you say that I am?” This is a question to the Church regarding persons with IDD that follows the example of asking his disciples, “Who do they say that he is?”

Much is revealed in how people talk about someone and as people of faith, this also carries responsibility. Talking about people, how the conversation is constructed, and the difference between stories and narratives as used in this project were clarified. Stories share an ordered telling of events that can either inform or develop understanding. Armed with this understanding and the knowledge of the Church’s social doctrine regarding all people and its principles of Tradition, the stage is set for the next step, which is to assess what this all means for individuals with IDD in the US Catholic Church.

I next explore the mutually informing relationship of ministry with persons with IDD in the US Church and its foundational theological vision, the *US Pastoral Statement*. I locate its roots within the essential insights of Vatican II that prioritizes the dignity of the human person, which undergirds all social doctrine and guides policies, actions and self-understanding about the essential nature of the Church. While this is

certainly present, I also notice a meta narrative about individuals with IDD interspersed throughout ministry activity, as well as the *US Pastoral Statement* that I named the *shadow narrative*.

In chapter three I unpack the *shadow narrative* and name its five threads, each one telling their own particular narrative and at times comingling with another of the threads. However, they all keep individuals with IDD marginalized within the US Catholic Church, which I the particular object of concern for this project. I make the case that a favorite book written by a beloved spiritual leader reinforces the most sentimental aspects of the *shadow narrative* and some of the problems it raises. Yet, I also noted some influential examples within Vatican and papal statements. The outcome of the *shadow narrative* reinforces the status quo regarding roles and positions in society and in the Church of persons with disabilities. This allows the Church to resist the tensions for change, even requires it do so in service of the *shadow narrative*.

From exploring one person's use of the *shadow narrative*, I looked into the history of a particular thread that informs its most maligned model, the charity model. Early Judeo-Christian roots are based on neighbor love and a covenantal relationship with God, but it picks up new influences as the two religions move through time and space. Some developments seek efficiency and/or consolidation of power, some developments stem from Greek or Roman cultural influences depending on the setting, and some a mixture of all the above. While it is not an exhaustive historical analysis, it is suggestive of possible influences on problematic patterns in charity today.

Chapters two through four provides historical inquiry and context of the problem. The last chapter probes the Church's self-proclaimed identity as the body of Christ and argued that the implications of this intended by Paul emphasizes interdependency and collective concern for the benefit of all, so that Christ may be made present in the world. This is consistent with the US Bishops' challenge to the US Catholic Church to maintain, "a spirit of mutual love ... [to] build a community of interdependent people and discover the Kingdom of God in [its] midst."⁴⁴¹ Such a body would be committed to the common

⁴⁴¹ USCCB, "US Pastoral Statement," par 2, 5.

good and open to the embodiments of the Spirit in the spaces between all within it, allowing for unknown possibilities to emerge as the body of Christ, both within its communal life, identity and its witness in the world. However, I asserted this is more nuanced than the typical presentation of the body of Christ, which tends to reinforce individualism with its focus on individual gifts.

These nuances, along with all that has been discussed so far about the *shadow narrative*, contribute to the deep ruptures between ecclesial statements and the lived experiences for many at the parish level. Remember, only 45% of individuals with severe disabilities participate in faith communities, compared to 57% of individuals without,⁴⁴² although 87% say that faith is important to them.⁴⁴³ Further evidence is the exodus of 32% of families from congregations because of wounding experiences when their son or daughter is excluded because of their disability, and 38% considering it for the same reason.⁴⁴⁴ These statistics reveal the disconnected experience between proclamation and practice at the parish level caused by the *shadow narrative* I identified and discussed in chapter three and contributes to the enduring marginalization which puts individuals with IDD at significantly greater risk of living in poverty and being subjected to bullying and personal violence.⁴⁴⁵

⁴⁴² Harris Interactive, "The ADA, 20 Years Later."

⁴⁴³ "2004 National Organization on Disability/Harris Survey of Americans with Disabilities."

⁴⁴⁴ Melinda Jones Ault, Belva C Collins, and Erik W Carter, "Congregational Participation and Supports for Children and Adults with Disabilities: Parent Perceptions," *Intellectual and developmental disabilities* 51, no. 1 (2013): p. 55; Elizabeth E O'Hanlon, "Religion and Disability: The Experiences of Families of Children with Special Needs," *Journal of Religion, Disability & Health* 17, no. 1 (2013): p. 52.

⁴⁴⁵ Petersilia, "Crime Victims with Developmental Disabilities: A Review Essay."; Blake et al., "National Prevalence Rates of Bully Victimization among Students with Disabilities in the United States."; D Almeida et al., "Perinatal Hospice: Family-Centered Care of the Fetus with a Lethal Condition."

How does the Church respond to these issues and turn back the tide on an undercurrent that has endured for centuries? Answering this question is the work of these next three chapters. It requires a framework to understand the landscape of the problem, the elements which have already been discussed, as well as a framework to construct a blueprint that can sufficiently respond to its challenges. *Social role valorization theory (SRV)* based on the work of Wolf Wolfensberger, who was introduced in the second chapter, will provide the conceptual structure to both understand and respond this enigmatic problem.

This chapter will introduce fundamentals of *SRV* to focus on the first task, understanding the landscape to be addressed. This will serve the purpose to shift focus from fitting persons with IDD into predefined spaces, thereby breaking down what Reynolds calls, the “cult of normalcy,” as discussed in chapter three. The next chapter will handle the second task, to construct a systematic response to the identified problem discussed throughout the text so far that reflects the changes called for by the Church in the *US Pastoral Statement*.

A. Social Role Valorization and the Growing End of Human Dignity

The US Bishops clarify the goal and suggest what needs to be done.

If people with disabilities are to become equal partners in the Christian community, injustices must be eliminated, and ignorance and apathy replaced by increased sensitivity and warm acceptance. The leaders and the general membership of the Church must educate themselves to appreciate fully the contribution people with disabilities can make to the Church’s spiritual life.”⁴⁴⁶

So, the goal is for persons with disabilities to truly be equal members within the Church, which the bishops acknowledge has been obstructed by the general indifference to their needs and desires, and nescience of what they are capable of and can contribute to the Church. The bishops then suggest that the task is threefold: eliminate injustices, replace ignorance and apathy with sensitivity and warm acceptance, and finally, the Church,

⁴⁴⁶ USCCB, “US Pastoral Statement,” par 13.

clergy, religious and pastoral leaders as well as the person in the pew, need to be reeducated about the abilities of individuals with disabilities. Actually, the bishops say they need to educate themselves. However, I suggest that it needs to be planned very intentionally to improve on the experiences of the past 42 years since the *US Pastoral Statement* was promulgated and 60 plus years since ministry with individuals with IDD was first organized at the national level. Reforming the Church, as in re-educating that leads to a new forming in faith is necessary. *SRV* is particularly useful for this task, because its presumptions, or rather the presumptions of its core, the normalization principle that was also introduced in chapter two, are based on human dignity and the belief that everyone should have access to what is known as *the good things in life*, making it very compatible with the core principles of Catholic Social Teaching.⁴⁴⁷

Remember the potent implications of human dignity from Vatican II. It established that all human beings had the right for freedom *from* religious coercion, as well as the right *for* access to things needed to live a human life.⁴⁴⁸ Catholic Social Teaching obligates the Church, collectively and its members individually, to base all actions on respect for the dignity of every person. So when considering individuals with IDD, it means believing in their potential to learn, develop new skills, make decisions, and supporting their right to education that supports this, participate in all areas of society, and even to take risks.⁴⁴⁹ To not do so denies their human dignity. I will say this again another way. When the Church engages with persons with IDD in any way based on stereotypic expectations defined by low expectations and diagnostic labels it denies their dignity; it denies the full implications of being created in the image of God.

⁴⁴⁷ Wolfensberger et al., *The Principle of Normalization in Human Services*; Bengt Nirje, "The Basis and Logic of the Normalization Principle," *Australia and New Zealand Journal of Developmental Disabilities* 11, no. 2 (1985).

⁴⁴⁸ Council Fathers of Vatican II, "Religious Freedom, Flannery," par 1-2; "Pastoral Constitution, Flannery," par 11-12, 23-32, 77-92.

⁴⁴⁹ "Pastoral Constitution, Flannery," par 11-32.

It seems certain Wolfensberger influenced key points of the *US Pastoral Statement*. He was writing and speaking widely during the 1970's about the devaluing and marginalizing practices of individuals with IDD in society and within the Church (paragraphs 2-3). Other themes of the *US Pastoral Statement* that Wolfensberger regularly argued: categorizations consistent with the *shadow narrative* (2-3), the impact of living out communality as the body of Christ (5-6), transformative implications of natural relationships within smaller communities and "real within fabric of society" (8-11, 14-17, 24, 26), and the importance of education and preparation of the community (13).⁴⁵⁰ So there is an elegant harmony between the *US Pastoral Statement* and a constructive strategy to implement it that is based on SRV.

Wolfensberger also pointed out that its principles could be applied just as effectively to other marginalized groups, elderly, immigrants, etc.⁴⁵¹ Therefore, bishops interested in social justice issues would likely be aware of Wolfensberger's work also. Beyond his national presence, however, a direct personal connection can be made with Auxiliary Bishop Thomas Costello of the Syracuse Diocese. Costello, recall, introduced the notion that integrated participation would increase natural relationships, which would ultimately reduce the need for institutionalization. He also sought "quality" over undefined "decent" care for persons with disabilities. As will be shown, these clearly reflect Wolfensberger's influence. Costello was known as a scholar who was passionate about social justice issues, he served on the US Bishops Social Development and World Peace Committee and its Communications Committee. A familiar quote of his

⁴⁵⁰ Wolf Wolfensberger, "An Attempt toward a Theology of Social Integration of Devalued/Handicapped People," *Journal of Religion, Disability & Health* 4, no. 2-3 (2001); "The Prophetic Voice and Presence of Mentally Retarded People in the World Today," *Journal of Religion, Disability & Health* 4, no. 2-3 (2001); Wolfensberger et al., *The Principle of Normalization in Human Services*. Reprints of earlier presentations, 1978 and 1976, respectively for Religion Division at national conferences for American Association on Mental Deficiency (AAMD).

⁴⁵¹ Wolf Wolfensberger and Robert Kugel, eds., *Changing Patterns in Residential Services for the Mentally Retarded* (Washington, D.C.: The President's Committee on Mental Retardation, 1969); Wolfensberger, *The Origin and Nature of Our Institutional Models*, pp. 23-33.

was, "It is not enough to be a believer. One must be a witness."⁴⁵² It is not surprising to know that the two men got along very well, and they both served food to many hungry people at Unity Kitchen in Syracuse.⁴⁵³

1. *Person-Centered*

Social Role Valorization assumes that all human beings are essentially social and thrive within relationships; all have the potential to learn, develop and grow; and there is a common understanding of what constitutes the good life.⁴⁵⁴ The vision and overarching purpose of *SRV* is to support access by marginalized individuals to a full and meaningful life within the major spheres of home, school, work, relationships, recreation/leisure and spirituality. The basis of this, of course, as was noted above on normalization, is that all persons are entitled to the good things in life, because of the innate dignity of every person.

Therefore, the process of *SRV* begins with the person, learning about their strengths, interests, support needs, dislikes, challenges, etc. It reassesses what apparent negative characteristics could be seen as positive, for example, where

⁴⁵² Webmaster, "Most Rev. Thomas J. Costello, Retired Auxiliary Bishop of Syracuse, Dies at Age 89," Diocese of Syracuse, <https://www.syracusediocese.org/news/most-rev-thomas-j-costello-retired-auxiliary-bishop-of-syracuse-dies-at-age-89/>.

⁴⁵³ Renée K. Gadoua, "Auxiliary Bishop Thomas J. Costello Dies at 89," The Catholic Sun 2019. <https://thecatholicsun.com/auxiliary-bishop-thomas-j-costello-dies-at-89/>. Additionally, I am grateful I am grateful to Susan Thomas for her insights into Wolfensberger's work, faith, perspectives and relationship with Bishop Costello in our phone conversation on 5/12/2020.

⁴⁵⁴ Wolf Wolfensberger, "Social Role Valorization: A Proposed New Term for the Principle of Normalization," *Intellectual and Developmental Disabilities* 49, no. 6 (1983): pp. 435-437; The Keystone Institute, "An Introduction to Social Role Valorization: A Framework for Assisting People to Have Full, Rich and Meaningful Lives: A Comprehensive SRV Workshop."; Wolf Wolfensberger, Susan Thomas, and Guy Caruso, "Some of the Universal "Good Things of Life" Which the Implementation of Social Role Valorization Can Be Expected to Make More Accessible to Devalued People," *International Social Role Valorization Journal* 2, no. 2 (1996): p 12.

obstinacy would be considered persistence. Or consider Larry, who had a high-pitched scream, which he tended to do when he wanted something, such as to be around people. However, since people tended to avoid him when he screamed, he screamed a lot. However, his screaming was strongly appreciated by a Minnesota community men's volleyball team when he started attending their games. He became their number one fan and considered part of the team. And, which is not uncommon in such cases, his screaming diminished in other settings.⁴⁵⁵

Hans Reinders shared Larry's story as an example of the ecological approach to inclusion. Rather than asking what to change about the person, the question becomes, "where would she flourish, where would his 'challenges' be received as gifts?"⁴⁵⁶ This lens recognizes the contextual implications of abilities, interests and support needs, such as the story about Larry that was just shared. All people will have places they shine, some they do okay in, and others that they are very uncomfortable in. Within the body of Christ, the presumption is that everyone is invited into deeper participation, but nothing is forced.

⁴⁵⁵ Angela Novak Amado, "Building Relationships between Adults with Intellectual Disabilities and Community Members: Strategies, Art, and Policy," *Research and Practice in Intellectual and Developmental Disabilities* 1, no. 2 (2014): p. 115; "Community Building, Friendships and Social Relationships," in *Developmental Disabilities Lecture Series* (Woodbridge Hilton, Iselin NJ: Elizabeth M. Boggs Center on Developmental Disabilities, 2011).

⁴⁵⁶ Hans S. Reinders, "Spiritual Encounter: The Power of Inclusion and Friendship," *Journal of Religion, Disability & Health* 15, no. 4 (2011): pp. 432-435.

2. Ten Basic Themes Help Access the Good Things in Life

Social Role Valorization presumes that every person should have access to the good things in life,⁴⁵⁷ which Catholic Social Teaching says are the things necessary for a fully human life. Further, that this is a concern for the larger community. SRV posits that these goods are more available to people in valued social roles and more elusive for individuals from marginalized groups. Therefore, a critical part of its framework emphasizes societal undercurrents that devalue groups of people and consequently marginalize them. Understanding this process provides insight to counter the devaluation, which SRV suggests can be achieved by enhancing a person's image and competency to participate within valued roles in a given community. It employs ten themes to develop a plan for a particular individual: implications of unconsciousness; symbolism and imagery usage; positive compensation for disadvantages, dynamics of interpersonal identification, the power of mindsets and expectancies; power of role expectations and role circularity, service model coherency; developmental model for personal competency enhancement, power of imitation and modeling, and personal social integration and valued participation within social roles and society.⁴⁵⁸

⁴⁵⁷ Wolfensberger, Thomas, and Caruso, "Some of the Universal "Good Things of Life" Which the Implementation of Social Role Valorization Can Be Expected to Make More Accessible to Devalued People," 12-14. Wolfensberger identified 17 things which are not listed in any particular order: family or small intimate group; a place to call home; friends; belonging to an intermediate size group; transcendent belief system, providing connection and belonging to wider human community and assistance with happenings in life; meaningful work; safety and access to necessities of life; opportunity to develop one's skills and abilities; respected as a person; treated honestly and fairly; justice; treated as an individual; a say in decisions of one's life; access to the ordinary activities and spaces of life; participate in ordinary human social life; to contribute to one's communities and be appreciated; good health.

⁴⁵⁸ The Keystone Institute, "An Introduction to Social Role Valorization: A Framework for Assisting People to Have Full, Rich and Meaningful Lives: A Comprehensive SRV Workshop." Days 1-4; Elizabeth Neville, ed. *An Introduction to Social Role Valorization: A Framework for Assisting People to Have Full, Rich and Meaningful Lives. Resource Manual for a Comprehensive SRV Workshop* (Harrisburg, PA: The Keystone Institute, 2017), pp. 74-214.

These ten themes could be organized into three categories to reflect their purpose: Analyze, Construct, and Test. ACT could be a mnemonic for remembering the general themes within SRV to counteract devaluing social undercurrents, which undermine opportunities for individuals with IDD to develop to their potential and gain access to the good things in life. Analyze the undercurrents affecting the person, Construct a plan for positive interpersonal engagement within social roles, and Test it for appropriateness and opportunities for role models and promoting positive expectations. According to Wolfensberger, he believed that a good life would look very similar for individuals with IDD as for people in general,⁴⁵⁹ even if there was some fluctuations based on culture.⁴⁶⁰

a. Analyze: Unconscious Mindsets & Symbolic Imagery

SRV spotlights the typically unconscious underpinning attitudes fueling the stereotypic narratives in the different threads of the *shadow narrative* that leads to devaluing and marginalizing individuals in congregational life. This is extremely important, because it is very difficult to address that which is *unconscious*, hidden in the shadows. Illumination makes it visible, where it can be addressed. Recall the discussion of this process in chapter three. SRV recognizes the importance of attending to this process and the implications of *unconscious mindsets* and *symbolic imagery*, both of which are very strong. *Mindsets* are most powerfully impacted by five types of experiences: first impressions formed, occur early in life, are intense, confirm believed stereotypes, and/or dramatically counter believed stereotypes. *Images* are chosen to reinforce these *mindsets* and provide strong *symbolic* associations without awareness, both positively and negatively. Just consider the amount of money

⁴⁵⁹ Wolf Wolfensberger, "The Good Life for Mentally Retarded Persons," *Journal of Religion, Disability & Health* 4, no. 2-3 (2001). Originally published in 1984 NAMR Quarterly.

⁴⁶⁰ The Keystone Institute, "An Introduction to Social Role Valorization: A Framework for Assisting People to Have Full, Rich and Meaningful Lives: A Comprehensive SRV Workshop." Days 1-4; Neuville, *An Introduction to Social Role Valorization: A Framework for Assisting People to Have Full, Rich and Meaningful Lives. Resource Manual for a Comprehensive SRV Workshop*, pp. 74-214.

companies spend on advertising if you think people in the Church are immune to their influence.

The next grouping of themes are used to *construct* a responsive plan, and could be considered most closely related to principles of social dynamics.⁴⁶¹

b. Construct: Interpersonal Identification, Personal, Positive Compensation, Valued Social Roles, Expectations

The quality and nature of social interaction is critical within SRV because of humanity's social nature. *Interpersonal identification* relates to community identity, covered in the discussion on marginalization in chapter three, which corroborates SRV's consistency with empirical studies in other disciplines. Still, it is worth reiterating because of its importance. *Interpersonal identification* refers to relatability with a person and is connected with identity drawn from being part of a particular group, which positively impacts empathic feelings toward members of one's group.⁴⁶² This requires proximity to develop, as do all of these themes actually.

Personal social integration presumes interpersonal interaction as well for authentic integration. The first emphasizes the *interpersonal*, while the second emphasizes the *communal*. Both are directly connected with *valued participation within social roles*.⁴⁶³ Because individuals with IDD are more often thought of for what they

⁴⁶¹ The Keystone Institute, "An Introduction to Social Role Valorization: A Framework for Assisting People to Have Full, Rich and Meaningful Lives: A Comprehensive SRV Workshop." Days 1-4; Neuville, *An Introduction to Social Role Valorization: A Framework for Assisting People to Have Full, Rich and Meaningful Lives. Resource Manual for a Comprehensive SRV Workshop*, pp. 74-214.

⁴⁶² Zaki, "Empathy," p. 1612; Wolf Wolfensberger, "A Brief Overview of Social Role Valorization," *Mental retardation* 38, no. 2 (2000): pp. 113-114. Wolfensberger refers to social context of identity here. A small number of devalued individuals within a larger group of socially valued people are socially valued; Raymond Lemay, "Social Role Valorization Insights into the Social Integration Conundrum," *Mental Retardation* 44, no. 1 (2006): pp. 1, 3.

⁴⁶³ "SRV on Social Integration Conundrum," pp. 1, 3-12; Wolfensberger, "A Brief Overview of Social Role Valorization," pp. 113-114.

cannot do, *positive compensation* for negative expectations is a significant concern. One creative example of this is the earlier story about Larry the number 1 fan. Again, *social roles* expect mutuality and reciprocity, which is critical for participation within community life. And finally, within the social dynamics grouping is *role expectations and role circularity*, which simply means that the expectations of someone in a particular role very often become assumed by the person performing the role. The final cluster of themes concerns implementation and *Tests* the support plan *constructed* for someone.⁴⁶⁴

c. Test: Developmental, Imitation Power, Coherency

SRV is founded on a *developmental* standard regarding human beings, which presumes that people prefer opportunities for flourishing and challenge, and that everyone has individual potential for growth when provided with appropriate support, appropriately high expectations, and opportunities to be engaged in the process. Therefore, goals are never static, but always evolving based on the individual person. While *development* occurs throughout the lifespan, the earlier such supports are available, the more potential can be realized. An important part of the learning process includes having *role models* to set examples for *imitation*, which requires being part of a community of diverse abilities.⁴⁶⁵ *Model coherency* tests that the plan serves the intended person and stated goals. More will be discussed on this in the next chapter.

Together, these ten themes cover important considerations to keep in mind when developing a plan for someone. Following is a brief summary organized within

⁴⁶⁴ The Keystone Institute, "An Introduction to Social Role Valorization: A Framework for Assisting People to Have Full, Rich and Meaningful Lives: A Comprehensive SRV Workshop." Days 1-4; Neuville, *An Introduction to Social Role Valorization: A Framework for Assisting People to Have Full, Rich and Meaningful Lives. Resource Manual for a Comprehensive SRV Workshop*, pp. 74-214.

⁴⁶⁵ The Keystone Institute, "An Introduction to Social Role Valorization: A Framework for Assisting People to Have Full, Rich and Meaningful Lives: A Comprehensive SRV Workshop." Days 1-4; Neuville, *An Introduction to Social Role Valorization: A Framework for Assisting People to Have Full, Rich and Meaningful Lives. Resource Manual for a Comprehensive SRV Workshop*, pp. 74-214.

mnemonic ACT. *Analyze* and *assess* the sources of devaluation and marginalization of the individual by identifying *shadow narrative* threads that are operative, reflecting *unconscious mindsets*. Also check for any *symbolic imagery* used when describing the particular individual or individuals with IDD in general. *Construct* a plan based on this information that fosters *interpersonal identification*, *personal social integration*, *positive compensation* and identifies *valued social roles* that includes opportunities to develop requisite skills to maximize opportunities for success. Then *Test* the plan. Is it developmentally appropriate? Are there natural supports built in, with positive *role models* for *imitation*? Is the plan *coherent*? Do the methods and strategies serve the stated goals and needs of the identified person? Next, I will explain how SRV unpacks the intertwined processes of devaluation and marginalization.

B. The Hermeneutics of Devaluation

A definition of SRV states that it applies empirical knowledge to enable, establish, enhance, maintain and/or defend valued social roles for people who are particularly at risk of being devalued, by using culturally valued means, as much as possible.⁴⁶⁶ This information essentially provides the key to breaking the code of the *shadow narrative* that reinforces the devaluation of individuals with IDD in the Church, which leads to their marginalization. Recalling that the bishops challenged “people of good will to reexamine their attitudes toward their brothers and sisters with disabilities,”⁴⁶⁷ it would seem they acknowledge the reality of prejudicial attitudes in the Church, and the marginalizing impact they have had regarding participation of individuals with disabilities within the Church. This is exactly what SRV seeks to explain and address.

⁴⁶⁶ The Keystone Institute, "An Introduction to Social Role Valorization: A Framework for Assisting People to Have Full, Rich and Meaningful Lives: A Comprehensive SRV Workshop," Day 2.;Neuville, *An Introduction to Social Role Valorization: A Framework for Assisting People to Have Full, Rich and Meaningful Lives. Resource Manual for a Comprehensive SRV Workshop*, pp. 119-120.

⁴⁶⁷ USCCB, "US Pastoral Statement," par 1.

SRV's principles can be applied within any environment. I will cite some examples from general community life, but most will be within congregational life, as that is my focus. It has tools to explain the process that has nourished the *shadow narrative* and eclipsed the light of the Gospel, as well as to counteract this based on the core premises of respect for human dignity that the Church also affirms. These facilitate developing strategies to facilitate interactions and opportunities to develop relationships amongst all within the parish communities, inclusive of persons with disabilities and other marginalized groups. The focus, however, is on getting to know the person, one person at a time. This requires getting to know each other with the full range of interests, passions, abilities and support needs and interests that includes increasing access to valued roles. Here valued roles are defined simply as any role within the Church in which someone will be missed if not present, and is respectful of the person, rather than reinforcing negative stereotypes.⁴⁶⁸ Partnered with increased role access includes increasing competency to perform these roles, which SRV says is necessary to counter the devaluation of persons with IDD by changing perceptions and assumptions about what they are capable of and increasing access to participating Church.

While SRV typically focuses on active roles, applied within the body of Christ, presence marked by connection and encounter are equally valued roles. Further, Wolfensberger frequently commented about the false goal of staunch individualism and independence rather than interdependence, a problem he attributed to modernity.⁴⁶⁹ Pia Matthews differentiates between participation characterized by activity and, "participation as "being." Both originate with encounter she says. Persons who are profoundly disabled, may only have the opportunity for the latter form of participation, yet that is no less valuable than the former within the body of Christ.⁴⁷⁰

⁴⁶⁸ The Boggs Center on Developmental Disabilities, "Employment Specialist Foundations Course," ed. Bethany Cox (Stanhope, NJ, Fall 2019).

⁴⁶⁹ Wolf Wolfensberger, "Social Role Valorization and, or Versus, "Empowerment", " *Mental Retardation* 40, no. 3 (2002): pp. 253-257.

⁴⁷⁰ Matthews, "Participation and the Profoundly Disabled: "Being" Engaged—a Theological Approach," p. 436.

Remember David Atkinson, introduced in chapter two, whose parents were advised to institutionalize him three times, when he was 3, 4 and 6 years old, because he was born with cerebral palsy. The doctors said he would never speak or live a life worth living. However, David contradicted their forecast of doom and retired from full time adult employment as a mail handler for the US Postal Service in New York City, where he commuted from Bergen County, New Jersey. He also retired from 45 years of service in parish ministry in 2016, as a greeter and hall monitor for the parish catechetical program. David responded to a bulletin notice for a door minister. He thought, "I can do that," and he did, welcoming generations of children, teens and parents over the years. When he read about support groups for parent of individuals with disabilities beginning, he thought, "I need to tell them my story," and he did. He was the voice of their sons and daughters, challenging the parents to have hope and believe in possibilities. David only retired because he was moving out of the area and into a facility for assisted living for the elderly (not for elderly persons with disabilities), and he is missed very much.

Renee Wood, who was introduced in chapter 3, scoffs when told she belongs to the Church through her baptism. She insists that many individuals with disabilities do not feel they belong, based on the way they are typically treated in the Church, isolated, marginalized and/or patronized. Renee has a pretty feisty spirit and speaks up for herself quite well. Her comments echo research done regarding the felt-sense lack of belonging by individuals with disabilities and their families.⁴⁷¹ Despite individuals like David, Renee, and many more, the *shadow narrative* has persisted within the Church, leaving the body of Christ incomplete and persons with IDD marginalized.

Paul, the father of 23-year old Adam, who has autism, had given up hope that there was a place for their family in the Church. He knew it professed concern to reach out to people who are marginalized. But their experience told them that the Church was interested in everyone, except their son and others like him. Although Paul did keep

⁴⁷¹ Erik W Carter, "From Barriers to Belonging," in *Summer Institute of Disability and Theology 2017* (Azusa, CA, 2017); "A Place of Belonging: Research at the Intersection of Faith and Disability," *Review & Expositor* 113, no. 2 (2016): pp. 167-180.

trying, his wife Janet was too hurt and disillusioned. Paul told his pastor about Inclusive Family Masses⁴⁷² that take place in the archdiocese, specifically for individuals and families living with disabilities who will not attend regular Sunday Eucharist. These liturgies serve to reach out and engage individuals with disabilities and families who do not attend their regular parish mass, either because they are afraid others will be distracted by their loved ones' behavior, or because they had bad experiences when they went. Paul asked if the parish would hold them as well. His pastor's response was, "there is just not enough time to do all good things." This pastor seems to have no idea what the Church is missing by the absence of Paul, Adam, Janet and Alexa, Adam's sister. When the Church turns away from individuals with disabilities, it not only loses that person, it loses the whole family.

1. Identity in Community – Roles vs. Gifts

Principles of social role theory are the foundation that SRV is built on. Wolfensberger became convinced that valued social roles were the real intent of the normalization principle. It advocated the need for individuals with IDD to have access to the 'normal' patterns of life that other people have, because it realized that learning and development happens within social interactions and the typical experiences of life. However, this was misunderstood by many, who thought the goal was to 'normalize' individuals with IDD or impose societal values and expectations on them. He felt the perceptions of individuals with IDD, which are very similar to the perceptions outlined in

⁴⁷² Inclusive Family Masses were established to reach out to individuals with disabilities and their families who will not attend their local parish liturgy, either because they are afraid of their loved one's distracting others or because they have been rejected when attending mass. It is stressed that all are welcome in the parishes of the archdiocese, but know there are families who still do not go. For more information, see Pastoral Ministry with Persons with Disabilities, "Inclusive Family Mass Schedule," Archdiocese of Newark, [https://www.rcan.org/sites/default/files/files/IFM%20Sept%202019-June%202020%20OLL%20not%20confirmed\(1\).pdf](https://www.rcan.org/sites/default/files/files/IFM%20Sept%202019-June%202020%20OLL%20not%20confirmed(1).pdf).

the *shadow narrative* earlier, was the issue to focus on.⁴⁷³ So to achieve its purpose, it was necessary to enhance their image by paying attention to relationships, physical settings, activities, etc. and to enhance their abilities via attention to these same things.⁴⁷⁴

This insight led to the emphasis on roles within human society. Human beings typically live and engage within multiple communities while performing various social roles. Therefore, SRV posits that valued social roles are the animating principle for participation and belonging within society. Catholic Social Teaching reflects and concurs with this understanding of the human person. Human development requires sufficient opportunity to actively engage in social relationships and community to develop initiative, abilities and social participation.⁴⁷⁵ This does not mean imposing specific expectations, but only to acknowledge that everyone is capable of learning and developing with proper access and support. The next few paragraphs will highlight the essential features of social role theory that SRV is built on.

a. Social Roles and Identity

The strongest and most enduring roles people have are *primary roles*, which transcend settings and provide opportunities for long-lasting reciprocal relationships, such as our parents and other family members. *Secondary roles* are contingent on location and/or purpose, for example, being a lector or greeter in one's congregation. Roles are interactive and reciprocal, meaning they do not exist in isolation. As a lector,

⁴⁷³ Wolfensberger, *The Origin and Nature of Our Institutional Models*, 2-17. Wolfensberger highlighted seven perceptions, among others noted, of individuals with IDD as: sick, a subhuman organism, as a menace, as an object of pity, as a burden of charity, as a holy innocent, or as a developing individual.

⁴⁷⁴ "Social Role Valorization: A Proposed New Term for the Principle of Normalization," 435-437.

⁴⁷⁵ The Keystone Institute, "An Introduction to Social Role Valorization: A Framework for Assisting People to Have Full, Rich and Meaningful Lives: A Comprehensive SRV Workshop," Day 3; Pontifical Council for Justice and Peace, "Compendium of Social Doctrine," par. 185-191.

there must be people listening to the Word proclaimed. To be a greeter, there must be people to greet and welcome. To be a friend, you must have a friend. This is called role incumbency and is important because of its interpersonal dynamism is significant for both developing competency and relationships, which is critical for success.

Often congregations focus on *activities* someone can *do* in the community, which are incidental and isolated from roles. Activities simply fill up time, whereas roles provide a basis for growth, interaction, participation, a sense of belonging and developing identity. Further, we are validated in these roles through people's acceptance and reinforcement of them. Conversely, we are disenfranchised through people's rejection of our roles.⁴⁷⁶ While SRV notes the social science of this, Catholic Social Teaching accepts and proclaims it. It is important to remember, however, that roles of action and being are both equally valued. The starting point is always the person. More will be said on this below.

b. Modeling – Practice – Cascading Roles

A young child depends on parents and other family members to help develop secondary roles, such as neighbor, playmate, helper, shopper, and/or student, but less so as they gain experience and competencies. As a person develops skills, both in number and type, secondary roles evolve and expand, leading the person to new primary roles which contribute to developing the multiple dimensions of personal identity and expanding participation within communities.⁴⁷⁷ Both SRV and Catholic doctrine affirm that the importance of participating in community settings is critical for human development and flourishing.⁴⁷⁸

⁴⁷⁶ Wolfensberger, "A Brief Overview of Social Role Valorization," pp. 110-112.

⁴⁷⁷ Lemay, "SRV on Social Integration Conundrum," pp. 5-10.

⁴⁷⁸ Council Fathers of Vatican II, "Pastoral Constitution, Flannery," par. 25-26.; Pontifical Council for Justice and Peace, "Compendium of Social Doctrine," par. 151, 185-188.; Wolfensberger, "A Brief Overview of Social Role Valorization," pp. 110-116.

This is a natural space for the Church to contribute.⁴⁷⁹ Because the Church heralds the importance of participation in community life as part of the development of the person, it can offer a safe space for such cultivation. Individuals can develop confidence as they participate in new roles within congregational life. This provides opportunities to form new friendships, that can lead to further opportunities to develop and contribute. Children becoming altar servers not only provides the opportunity to serve in liturgy, they also become visible to the community at large, independent of their parents. This can also foster relationships with the person who educates them and then becomes a mentor in faith, other liturgical ministers and clergy, as well as peers. Learning is much stronger within a diversity of people with different abilities, even different levels of abilities, and is much weaker in segregated spaces. There are also more opportunities to develop diverse relationships, which cannot happen without interaction.⁴⁸⁰

A person of any age who joins the music ministry shares a gift of music with the community, and meets other people who enjoy music. Such roles and experiences can lead to further connections and possible roles in the community and beyond. For example, a young man who enjoys nature, and the outdoors, has a lot of energy and lives with autism became an apprentice to the gardener in his congregation, which eventually led to a paid position with a landscaping company.⁴⁸¹

c. Presence

To have a presence within a community, one must be present, at least enough to form connections with people. Contrasting the active roles described so far, there is also room within the body of Christ to value the presence of “being”, which helps the person be and feel part of something larger than one’s self, the body of Christ. This is also a

⁴⁷⁹ USCCB, "US Pastoral Statement," par. 11.

⁴⁸⁰ Lemay, "SRV on Social Integration Conundrum," 1-5.

⁴⁸¹ Bill Gaventa et al., "Putting Faith to Work: The Call and Opportunity for Faith Communities to Transform the Lives of People with Disabilities and Their Communities," (Kentucky, LA: Vanderbilt Kennedy Center, UCEDD, 2014), p. 12.

secondary role, rooted in presence and participation within local congregational life, though one could argue that this also falls within one's primary role as part of the body of Christ. The act of *being* present is integral to the role of witness, *being* in liturgy, hearing the Word, sharing in eucharist, every member is an important part of the whole, and the Spirit manifests in the spaces in between (1 Cor 12 4-7). Every witness provides witness to each other and the whole, living "charity in a fraternal way," and provides witness to the world.⁴⁸² The important point to note is that what form the role of witness takes is the person's choice, rather than a presumptive result of false expectations and stereotypes.

Another example demonstrates possibilities for someone more significantly impacted by disability. Anna was diagnosed with a sort of mitochondrial disease in the same family as Parkinson's when she was nine months old. Prior to that she had been developing typically, and did continue some development until she was two years old, after which, she began losing abilities. When Anna was two years old, she was blind and deaf and had no verbal expressive language, though she could communicate on some level. The doctors thought her comprehension was fine, though they had no way to confirm this. When enjoying something she would typically smile and rub her belly. Church was pretty much the only place Anna went outside of home, other than doctor appointments, and the evidence seemed to indicate she enjoyed it. Parishioners embraced her when she went to mass, respectfully and with sincere interest. They had remembered when she was first diagnosed with the condition and had been a supportive presence for the family.

By all accounts, Anna was actively present in the liturgy and with the other people in the parish, part of the worshiping community. Her condition was declining steadily and by the time she was five, she had frequent respiratory ailments, which would increase her decline. Anna's older sister was to have her First Celebration of Eucharist in a few months and the parents wondered if she could possibly do so as well,

⁴⁸² Pope Paul VI, "Evangelii Nuntiandi (Proclaiming the Gospel)," (Vatican City: Libreria Editrice Vaticana, 1975), par 15.

they did not know if she would make it to her seventh birthday. The answer was yes, of course. Anna had been actively engaged in the faith as she was able, and there was no reason to delay. Less than a year later, Anna died, leaving the imprint of her life behind her.

Matthews' discussion of 1 Cor 12: 26-27 implies that if individuals with disabilities are absent, the community is incomplete, which concurs with the earlier discussion of the text. "[S]imply concentrating on enabling people with disabilities to do as far as is possible what others do risks overlooking their own rather specific contribution."⁴⁸³ Recognizing active presence in silence makes space for appreciating the participation of persons who are profoundly disabled, not because they provide opportunities for service by others, to become more like Christ, but in providing a presence of 'being' rather than 'doing', each uniquely.⁴⁸⁴ Matthews cautions against presumptive responsibility taken for persons with profound disabilities. Yes, justice does require responsibility is claimed, but in the spirit of accompaniment, walking "*with*" the person. Rather than seeing the person as an extension of one's self, appreciating the person as totally "other" who is "'a whole' also has his or her activity even if this is difficult to grasp by the more active other."⁴⁸⁵ In other words, that members of Anna's parish could appreciate her as a complete person, who was totally distinct from each of them. Without her being physically present, the parish would not have had the benefit of Anna's particular presence.

The principles of SRV provide the framework for this accompaniment, not by imposing cultural norms on to Anna, but through recognizing her uniqueness and differences from one's self, and realizing just because she may not be able to speak and share thoughts, does not mean she is not thinking or not understanding what people are saying. Anna was a parishioner, with all the benefits and obligations the role

⁴⁸³ Matthews, "Participation and the Profoundly Disabled: "Being" Engaged—a Theological Approach," p. 435.

⁴⁸⁴ Ibid., pp. 428-30, 435-436.

⁴⁸⁵ Ibid., p. 433.

entails, the parish valued her presence and misses her now that she has died. Her presence witnessed her faith and that of her parents and of the congregation.

SRV emphasizes the importance of valued social roles to enhance perceptions of persons with IDD. This happens both by being in the role and demonstrating the ability to fulfill the role, which changes people's expectations. *SRV* does not refer to gifts, which are not interpersonal by definition, although their realization can be the result of development that occurs through participating in valued social roles. This is a helpful insight for the Church. The Church talks so much about gifts, Gifts of the Spirit. As discussed in the last chapter Paul's intent in 1 Cor 12 was to emphasize the interactive manifestations of the Spirit within the spaces between all in the body of Christ. The interactive and interpersonal nature of social roles reminds the Church of the opportunities and responsibilities to each other, rather than focusing on evaluative categories. Within disability discussions, acknowledging gift is common to offset the predominant view that persons with disabilities need to be taken care of, and therefore have nothing to offer, except perhaps, "their appeal to people's better nature," as noted in the *shadow narrative* charity thread. Such an attitude is rightly rejected, and it is important to note that individuals with disabilities do each have their own gifts to contribute to relationships and community life, as all people do. However, the reciprocity of social roles is an important dimension of community life that reinforces the Church's identity as a communion.

Sadly though, as stated at the outset of this thesis, this is not the typical experience for individuals with IDD in the Church. Next, I will discuss how *SRV* addresses marginalization, or said another way, how it addresses people who are living lives that are framed by the *shadow narrative*.

2. Living Within the Shadow Narrative

Early in this project I identified the *shadow narrative* that has been diminishing the light of the Gospel, causing the intersection of theology, disability and pastoral

practice to be disconnected within the body of Christ, undermining its very existence.⁴⁸⁶ Recalling two examples from the early days of NAMR, within its mission it noted as part of its reason was for “the positive Christian attitudes they [individuals with IDD] stimulate in others,”⁴⁸⁷ and the words of its first episcopal moderator noting NAMR’s importance, “to provide for the care and training of these best loved children of God. I refer to these little ones as “exceptional children” because they afford us an exceptional opportunity of service.”⁴⁸⁸

Wolfensberger would maintain that Cardinal Cushing’s characterization of individuals with IDD as “exceptional children” and “little ones” casts individuals with IDD as forever children, lacking in the ability to grow and develop.⁴⁸⁹ As such, it must be acknowledged that no matter how kindly Cushing’s intentions may have been, this undermines the very essence of Catholic Social Teaching, which acknowledges the ability of everyone to learn and grow, and treats this as a justice issue. Understanding and exposing the source of the unjust marginalizing structures perpetuated by the *shadow narrative* is critical if a sense of belonging is to be cultivated.

Remembering the response of Paul’s pastor, his response implied that seeking to help Adam feel comfortable and welcome within the Church was “a nice thing to do,” but not necessary or important. It is not a far stretch then to feel, as Paul felt, that Adam is considered expendable to the Church. The Church needs to integrate its theology and current knowledge within its pastoral practice to be deemed credible, by its members

⁴⁸⁶ Pope John Paul II, "Mane Nobiscum Domine (Stay with Us Lord), Apostolic Letter for Year of the Eucharist," (Vatican City: Vatican Publishing House, 2004).

⁴⁸⁷ "National Apostolate for the Mentally Retarded Constitution Excerpts."

⁴⁸⁸ Cushing, "Letter to Fr. Matthew Pesaniello," p. 2.

⁴⁸⁹ Wolf Wolfensberger, "An “If This, Then That” Formulation of Decisions Related to Social Role Valorization as a Better Way of Interpreting It to People," *Intellectual and Developmental Disabilities* 49, no. 6 (2011): 457-459.

and the world.⁴⁹⁰ It also risks leading “people of good will”⁴⁹¹ astray, through the rippling tides of harm that can be inflicted when the Church does not live what it proclaims. Parishioners and others observe such self-interested behavior and can be (mis)informed by it, both children and adults.

Social role valorization recognizes the wounding that devalued persons experience, which participates in their further marginalization into the spaces known as OTM, and restricts their access to what Wolfensberger calls the good things in life, which is essentially the same list already discussed that the Council Fathers use to list the things deemed necessary for a fully human life.

a. Wounds and Legacy of Low Expectations

Socially devalued individuals are used to being defined by what they cannot do, rather than what they can do.⁴⁹² The experience of devaluation contributes greatly to developing additional devalued characteristics, leading to further devaluation of the person and to increasingly low expectations. Frequently such individuals then resist contrary expectations, because they have become comfortable with the consequent restricted and marginalized spaces, they have essentially become ‘narrated’ into a restricted sense of themselves. Internalized oppression becomes part of their

⁴⁹⁰ Pope John Paul II, "Stay with Us Lord," par 28.

⁴⁹¹ Pope John XXIII, "Pacem in Terris." Pope John XXIII wrote to “all people of good will,” including all people in the world, not just within the Catholic Church. Since then most church documents are also addressed to the world. I use the term here to raise concern about the harm that is done when the Church does not live what it proclaims.

⁴⁹² Carter, "From Barriers to Belonging."; Angela Novak Amado, "Friends. A Manual for Connecting Persons with Disabilities and Community Members," (1990): pp. 42-48; "Building Relationships between Adults with Intellectual Disabilities and Community Members: Strategies, Art, and Policy," p. 114; Erik W Carter et al., "Known for My Strengths: Positive Traits of Transition-Age Youth with Intellectual Disability and/or Autism," *Research and Practice for Persons with Severe Disabilities* 40, no. 2 (2015); Carter, "A Place of Belonging: Research at the Intersection of Faith and Disability."

narrative.⁴⁹³ Devaluation does not just restrict access to resources for a fully human life. It wounds people by diminishing their sense of self and increasing their sense of isolation, they can be scapegoated, etc. Wounded individuals can become socialized into a “legacy of low expectations,” through this circularly reinforcing narrative of increasingly diminished prospects. Such despair can also be passed on to future generations.⁴⁹⁴

These wounds are lasting, they leave marks, just as physical wounds do, and they pile up on a person. However, the wounds are hidden to the outside world, who judges the individuals based on their impact, perpetuating their legacy further. These wounds also cast a shadow on family members, who can feel marginalized by the shadow cast on their loved ones.⁴⁹⁵ Physical or functional deficit-based identity is typically the first level of wounding that subsequently leads to additional wounds and downwardly spiraling experiences. Persons with IDD then feel rejected through reduced social status by family, neighbors, and/or church, etc. This may not be intentional, yet the person feels it just the same.

Dismissed by others for having reduced cognitive abilities, and therefore presumed reduced awareness, the person can feel deep pain from a sense of a wasted

⁴⁹³ Eric John Ramos David and Annie O. Derthick, "What Is Internalized Oppression, and So What?," ed. Eric John Ramos David, *Internalized Oppression: The Psychology of Marginalized Groups* (New York: Springer Publishing Company, 2013). 1-30.

⁴⁹⁴ Wolfensberger, "A Brief Overview of Social Role Valorization," pp. 105-107, 110-111; The Keystone Institute, "An Introduction to Social Role Valorization: A Framework for Assisting People to Have Full, Rich and Meaningful Lives: A Comprehensive SRV Workshop."Days 1 and 2.

⁴⁹⁵ Wolfensberger, "A Brief Overview of Social Role Valorization," pp. 107-109; The Keystone Institute, "An Introduction to Social Role Valorization: A Framework for Assisting People to Have Full, Rich and Meaningful Lives: A Comprehensive SRV Workshop."Days 1 and 2.

life and being the cause of anguish for loved ones.⁴⁹⁶ A pastor says a woman with autism cannot explain transubstantiation, so access to the sacramental life is not important. Though 24, a young man is considered to be like a three-year-old, so his adult dog that died was replaced with a puppy, telling him it shrunk. When a mother refers to her adult son with Down Syndrome as her “sweet cross,” it hardly fosters his self-confidence. When a woman’s church decides she should go to the “special” program with 10-year-olds, because she ‘functions as an eight-year-old,’ though 32 years old, she understands they are different. The isolation and diminishment felt in “segregated and congregated”⁴⁹⁷ environments amplifies powerlessness and perpetuates discontinuity in relationships, home, and/or school, etc. Although they recognize the inappropriateness at first, over time, it begins to feel “normal.” Further isolation and diminishment is experienced through a lack of natural relationships that are replaced with paid ones. One’s individuality is lost through forced groupings of people “just like you.” Impoverished life experiences continue to accumulate, by being excluded from typically valued or enriched experiences, and higher-order value systems, such as faith communities, are deemed irrelevant.⁴⁹⁸

The vignettes interspersed in the paragraph above are individual experiences of a number of persons with IDD I have met or heard of in the course of my work. The examples illustrate typical layers of wounding experiences that characterize the lives of persons with IDD and influences expectations of them. It tells a story of despair deprived of life’s natural development, which can lead to listlessness, distrust, and/or anger. I have witnessed all three of these. Pope Francis calls out structures that wound

⁴⁹⁶ "An Introduction to Social Role Valorization: A Framework for Assisting People to Have Full, Rich and Meaningful Lives: A Comprehensive SRV Workshop," Day 1.

⁴⁹⁷ This phrase is frequently used within SRV to not the practice of isolating persons with IDD into homogeneous groups. For example, see Lemay, "SRV on Social Integration Conundrum," p. 5.

⁴⁹⁸ The Keystone Institute, "An Introduction to Social Role Valorization: A Framework for Assisting People to Have Full, Rich and Meaningful Lives: A Comprehensive SRV Workshop," Day 1.

and deny a person's dignity as sinful.⁴⁹⁹ The demoralizing impact caused by such on-going suffering and injustice perpetuates a cycle of diminished hope, betrayal, and unworthiness, inured to injustice.

Bringing consistency to pastoral practice concerning persons with IDD requires recognizing the impact of such wounding experiences and learning how to respond to such social dynamics and identity development. Remember the earlier discussion on charity. As a man of faith, Wolfensberger, challenged faith communities to evaluate the synergy between their practices and creedal statements.⁵⁰⁰ He would heartily agree with Benedict XVI that good intentions and creedal professions can fall apart when they are simply vague theological pronouncements that ignore human interaction.⁵⁰¹ Clarity about how these should be reflected within congregational life is critical, according to Wolfensberger.⁵⁰² Such is consistent with the essential outcome of the Second Vatican Council. The Church, collectively and in the life of its members, needs to reflect what it proclaims within the details of life.⁵⁰³

⁴⁹⁹ Pope Francis, "Evangelii Gaudium (Joy of the Gospel)," par. 67, 99-100.; "Looking for Mercy," par. 7, 15.; *Amoris Laetitia (the Joy of Love)*. par. 245.; "Gaudete Et Exsultate (Rejoice and Be Glad)," par. 67, 76.; Meghan J Clark, "Pope Francis and the Christological Dimensions of Solidarity in Catholic Social Teaching," *Theological Studies* 80, no. 1 (2019): p. 116. Paraphrasing Pope Francis during his, "Visit to the Astalli Centre," Clarke says, the "violence of poverty and exclusion leaves people wounded," and "the culture of indifference leaves unseen wounds, separating one from God."

⁵⁰⁰ Wolf Wolfensberger, "Response to the Responders," *Journal of Religion, Disability & Health* 4, no. 2-3 (2001): p. 150; "Attempt toward Theology," pp. 59, 66; "The Good Life for Mentally Retarded Persons," pp. 104-107; "Prophetic Voice and Presence," pp. 31-40.

⁵⁰¹ Pope Benedict XVI, *Caritas in Veritate (Charity in Truth)*. p. 13.

⁵⁰² Wolfensberger, "Social Role Valorization: A Proposed New Term for the Principle of Normalization," p. 439.

⁵⁰³ Council Fathers of Vatican II, "Message to Humanity, Abbott," L417-432.

So far, I have introduced *SRV*, why I think it provides the needed framework to understand the force of the *shadow narrative*, it's synergy with the earlier discussion on marginalization and some examples within the Church. Next, I will present counter arguments to common criticisms of the theory, thereby furthering its case.

C. Criticisms of SRV

There are two popular criticisms of *SRV* that I often confront, which were also active in the early days of the normalization principle and throughout Wolfensberger's career. Oddly enough, it is easier to find criticisms of *SRV* in the response of *SRV* authors and teachers, than finding articles criticizing it.⁵⁰⁴ One says that persons with IDD are happier in segregated spaces, with other like *themselves*, or they will learn better, or be able to participate better. The second criticism has two strands. Its overarching argument says that *SRV* devalues the people it claims to serve, by forcing them to fit into normative roles dictated by society that disrespect the person. Often associated with this criticism is the challenge to confront society's norms and values by advocating for people's choices, without considering the implications for the individual.

1. Happier With Others Like Themselves

The first criticism to address, which has connections with the *forever child shadow strand*, is the response "but they are happier with others like themselves" or "they will understand so much better."⁵⁰⁵

⁵⁰⁴ Wolfensberger, "Attempt toward Theology," 65-70; "The Normative Lack of Christian Communalism in Local Congregations as the Central Obstacle to a Proper Relationship with Needy Members," *Journal of Religion, Disability & Health* 4, no. 2-3 (2001); "An "If This, Then That" Formulation of Decisions Related to Social Role Valorization as a Better Way of Interpreting It to People."; Wolfensberger, Thomas, and Caruso, "Some of the Universal "Good Things of Life" Which the Implementation of Social Role Valorization Can Be Expected to Make More Accessible to Devalued People," 12; Wolfensberger, "Social Role Valorization and, or Versus, "Empowerment", 253-257; The Keystone Institute, "An Introduction to Social Role Valorization: A Framework for Assisting People to Have Full, Rich and Meaningful Lives: A Comprehensive SRV Workshop," Day 4.

⁵⁰⁵ Wolfensberger, "Attempt toward Theology," 65-67.

a. Better Together

The first position, Wolfensberger said, assumes that out of all the different characteristics and qualities that make up the identity of a person, the one that matters most is their IQ or diagnosis, or at least, for individuals with IDD.⁵⁰⁶ The second assumes that faith is predominantly cognitive concern. He thought both positions absurd. Not only do segregated placements increase isolation and disconnection, they undermine the development of communal identity, ignore known pedagogies of how people learn, which includes access to diverse modeling opportunities, as well as isolates people.⁵⁰⁷ How does someone develop a sense of belonging in a community in which one's presence is marginalized?

This seems particularly an issue within the body of Christ, which if authentic, is a place where embodiments of the Spirit elicit new possibilities through the interactions of the different and diverse members, in the spaces in between them. This moves beyond social integration because needs and abilities of each and all are mutually shared.⁵⁰⁸ Such interconnectedness is what is claimed as the body of Christ, as discussed in the last chapter (1 Cor 12: 1-28).⁵⁰⁹

Wolfensberger challenged faith communities to consider the implications of segregation and inconsistent attention against purported belief statements,

To the call to love my neighbor as myself, can't we assume my neighbor should be around to be loved and restricted no more than me? When we justify the segregation of people because of arbitrary characteristics, "are we not bearing false witness against that which defines these people (now devalued) as our brothers and sisters?" Given the proof that discontinuity in

⁵⁰⁶ Ibid., 59, 65-67.

⁵⁰⁷ Lemay, "SRV on Social Integration Conundrum," pp. 3-10.

⁵⁰⁸ Wolfensberger, "Attempt toward Theology," pp. 111-120.

⁵⁰⁹ USCCB, "US Pastoral Statement," par. 12, 13; Pontifical Council for Justice and Peace, "Compendium of Social Doctrine."par 204-208

residence and relationships 'hastens death' of vulnerable people, what about, "though shalt not kill?"⁵¹⁰

These questions give pause for thought when framed within God's commandments. There is plenty of contemporary validation that individuals with disabilities share the desire to belong and contribute within their faith community in an *ordinary* way, within the natural rhythms and life of the community.⁵¹¹ Wolfensberger ardently challenged whether any segregated practices could be considered truly Christian and insisted that catechetical ministry should focus on purpose, rather than seeing itself as an object.⁵¹² He dismissed the sentimental stereotypes about individuals with IDD, that they are: more loving, simple of heart, relational or holy innocents. He believed that such characteristics were better explained by the social realities of their lives and were examples of adaptive learning. Not only are their relationships typically more fragmented and fleeting, but they are often significantly more dependent on others for access to things and activities than people who aren't devalued and marginalized.⁵¹³

In other words, persons with IDD learned there were benefits to demonstrating such characteristics, and Wolfensberger considered them to be demonstrating the ability to learn, engage in, and influence the world they inhabit. Although he was impressed with L'Arche in his early years, Wolfensberger later challenged it for its segregation from community life, though he also acknowledged it was a partial

⁵¹⁰ Wolfensberger, "Attempt toward Theology," p. 59.

⁵¹¹ Carter, "A Place of Belonging: Research at the Intersection of Faith and Disability."; Reinders, *Receiving the Gift of Friendship*; *ibid.*; Reinders, "Spiritual Encounter: The Power of Inclusion and Friendship."; Living Fully Team, "Statement and Charter from Living Fully 2016: Disability, Culture and Faith: A Celebration," *Culture e Fede, Pontificium Consilium de Cultura, CIVITAS VATICANA* xxiv, no. 3 (2016). Output of the Living Fully conference with input from a number of delegates with disabilities.

⁵¹² Wolfensberger, "Response to the Responders," p. 150.

⁵¹³ "An Attempt to Gain a Better Understanding from a Christian Perspective of What "Mental Retardation" Is," *Journal of Religion, Disability & Health* 4, no. 2-3 (2001): p. 81.; "The Good Life for Mentally Retarded Persons," p. 104.

exception to the dearth of Christian communality at the time.⁵¹⁴ This provides an interesting counter point to Vanier's caution in *Community and Growth*, which I have already contested, that persons with IDD "should not be sucked into structure of the community; that would deflect them from their gift, which is to love...to call out for love and awake compassion and service in the hearts of others."⁵¹⁵

2. Devaluation by Denying Choice

The second popular criticism of SRV says that it forces individuals to fit into normative roles dictated by society that disrespect the person. The argument continues that this discounts their choices, thereby reinforcing the devaluation it claims to address. Often associated with this critique is the challenge to confront society's norms and values by advocating for people's choices without considering the implications for the individual.⁵¹⁶ The concern is that marginalized people are told they need to fit in to society as it is, and thus perpetuates the devaluation it purports to overcome. *SRV* counters this with three points in particular, respect, assume someone's possibilities for abilities, and focus on individuals for greater success and effectiveness. I will touch on these briefly below.

a. Respect and Assume Ability

Like any process, it can be abused and misused by simply imposing another's ideas onto someone. Properly done, however as has already been discussed, the

⁵¹⁴ "Response to the Responders," p. 150.

⁵¹⁵ Vanier, *Community and Growth*, p. 263.

⁵¹⁶ David Race, Kathy Boxall, and Iain Carson, "Towards a Dialogue for Practice: Reconciling Social Role Valorization and the Social Model of Disability," *Disability & Society* 20, no. 5 (2005): 507-519; Wolfensberger, Thomas, and Caruso, "Some of the Universal "Good Things of Life" Which the Implementation of Social Role Valorization Can Be Expected to Make More Accessible to Devalued People," 12. The authors for Race article were actually voicing critique of SRV by proponents of the social model of disability in UK, but in their review found that *SRV* had positive contributions to make and is not guilty of the charge. I also appreciate the lively conversations with my fellow PHD seminar students.

starting point is the person, honoring how she learns, exploring how people typically learn the role and become established in it, to the fullest extent possible, while also diminishing dependence on external human service supports. The basic premise is that everyone, inclusive of individuals with disabilities, have the ability to learn and develop.

However, SRV only indicates likely results of different actions taken. It does not teach taking things away from people including personal possessions, or preferred roles, or dictating to people what they must do. But it does recognize the likelihood of providing greater access to the good things in life by how the community perceives individuals and values their roles in the community.⁵¹⁷ This lens reflects the relational and social dimensions of the good life, which is a central component of SRV as well as Catholic Social Teaching.

A fair question to raise at this point is if this criticism of SRV conceals a bias toward staunch individualism. Is the person being served so inclined? Does he wish to be seen as so different from the general community in which he wishes to belong? People with socially valued currency can afford such choices more than those who are struggling to be valued, which has already been discussed. When challenging culturally valued roles, there is also the assumption that asserting someone's right to choose is more respectful of the person. Yet, does this mean an unqualified acceptance of their choices to define their life, without education and support to develop this ability? For example, if Jim says he wants to play video games all day, is that really in his best interest? Does supporting such a plan really respect his ability to learn and grow? Does he even have sufficient information to make a decision?

Jim may not be interested in a job, but he might be very interested in earning a paycheck. Alternatively, what about accepting Beth's choice without identifying an authentic path for her to achieve it? If she wants to become a chef, but does not have the skills to communicate within a busy restaurant environment, what are her chances for success? What is the long-term sustainability of either plan in comparison to a plan that works with Jim and Ben to identify roles that they are interested in and plans for

⁵¹⁷ Reinders, "Spiritual Encounter: The Power of Inclusion and Friendship."

success? Beyond this the ability to make decisions is a skill that is developed through practice, education and guidance. Recall Perske's advancement of the 'dignity of risk' in the discussion on the normalization principle in chapter 2. He insists that protecting people from the 'risk' of failure is 'a dehumanizing indignity in safety.'⁵¹⁸ Such plans would explore their gifts, strengths, inclinations and support needs, as well as identify how to develop new skills, that can lead to future development in their roles, as well as to a network of social roles which connect to their desires for a good life.

Recall that the heart of *SRV* believes that every person deserves access to the good things in life, that everyone can learn and develop when properly supported, and that the good things in life are more elusive for groups of people who are devalued by the normative culture. Therefore, the essence of *SRV* is to provide a framework to launch individuals with IDD into the world, to the extent that is possible for them. Not supporting this denies the dignity of individuals with IDD. Although progress has been made, the sad reality is that many individuals with IDD have been raised and educated with low expectations that have not prepared them to make informed decisions or adequate support for meaningful employment.

Remember also that a basic premise of *SRV* states that one builds social capital through valued social roles, not merely by engaging in activities related to an interest or skill. The difference between roles and activities is significant. Activities simply fill up time. Roles provide opportunities to interact with others, form relationships and develop abilities to participate and contribute within the community. However, Wolfensberger believed that not supporting the developmental process for participating within community life was simply "dumping" people into the community.⁵¹⁹ This is unacceptable as well.

⁵¹⁸ Perske, "The Dignity of Risk and the Mentally Retarded," p. 6.

⁵¹⁹ Wolfensberger, "Social Role Valorization and, or Versus, "Empowerment", " pp. 253-257.

b. Effectiveness With Individuals

Wolfensberger understands the criticism of *SRV* that is concerned it tells marginalized people they need to fit into society as it is, and thus perpetuates the devaluation it purports to overcome. He responds, "It is, of course, understandable that people – especially devalued ones – would deeply resent the fact that others are making value judgements about them, and that these judgments affect their social status and well-being in a negative way."⁵²⁰ However, while elements of *SRV* can be useful for developing awareness and fostering change to the larger culture, it requires a much more involved effort to effectively address such systemic structures. Working for the benefit of an individual person will almost always be more efficient and effective, because there is a strong feedback loop to enhance image and competency at the micro level, which could include small organizations.⁵²¹

This does not mean to not work on the macro level. In fact, this is a place the Church can make a difference, as the *US Pastoral Statement* says, to make persons with disabilities "real within the fabric of modern society."⁵²² The persistent marginalization of persons with IDD in the Church, despite protestations to the contrary, indicates the complexity of the task. While the bishops say it requires education, Susan Thomas notes that education alone is insufficient without attention to the influence of attitudes.⁵²³

⁵²⁰ Ibid., p. 255.

⁵²¹ Wolfensberger, "A Brief Overview of Social Role Valorization," p. 122.;The Keystone Institute, "An Introduction to Social Role Valorization: A Framework for Assisting People to Have Full, Rich and Meaningful Lives: A Comprehensive SRV Workshop."

⁵²² USCCB, "US Pastoral Statement," par 11.

⁵²³ Susan Thomas, "Historical Background and Evolution of Normalization-Related and Social Role Valorization-Related Training," in *A Quarter-Century of Normalization and Social Role Valorization: Evolution and Impact*, ed. Robert A. Flynn and Raymond Lemay (Ottawa: University of Ottawa Press, 1999), p. 354.

Beyond pragmatic issues, however, is a more important concern. Choices that do not respect the dignity of every person discredits the call to love. Respect requires honest and openness to new possibilities. Without honesty, sincere respect is missing.⁵²⁴ The young man with Down Syndrome noted earlier, who was told a puppy was just the shrunken version of his adult dog, is an example of this, which the family eventually realized. At the same time, it is important to note that of course within the body of Christ, this respect includes valuing new possibilities based on the individual person. This was positively revealed in the story of Anna. The Church as the body of Christ is called to receive each other in love, just as we have each received the unmerited gift of love from God.

D. Social Role Valorization and Change Agency

In this chapter I outlined the framework that *SRV* provides to understand the forces that marginalize individuals with IDD in the US Catholic Church and denies their essential dignity as a person. This started with first introducing its essential principles about identity formation that is based on social role theory and the importance of participating in valued social roles to have access to the good things in life, or what Catholic Social Teaching says is necessary to live a fully human life. Presuming that everyone is able to learn and develop when properly supported, *SRV* also outlines how individuals from outside the '*cult of normalcy*' are devalued and consequently marginalized, which sets off a legacy of low expectations that spiral into further wounding experiences. Countering this, *SRV* posits, requires providing access to valued social roles along with support to develop the appropriate skills. But it must be done properly, based on the individual's interests, desires and reasonable ways to begin. Rather than imposing goals, *SRV* suggests likely outcomes for particular choices and provides tools that will enhance listening and accompaniment.

Understanding the dynamics of marginalization is necessary to effectively overcome it, to become effective change agents. This was the essential object of *SRV*

⁵²⁴ Pope Benedict XVI, *Caritas in Veritate (Charity in Truth)*. par 2-7, 9, 11, 13, 17, 19, 30, 34, 57.

and Wolfensberger believed that people must realize there are consequences for both actions taken and not taken.⁵²⁵ Indeed, serving as a change agent was so important to him, that he coined the phrase “change agency” when establishing the Institute at Syracuse University, “Training Institute for Human Service Planning, Leadership and Change Agency.” According to Merriam-Webster dictionary, agency refers to the office, duties or activities of an agent.⁵²⁶ Change agents were therefore supposed to effect change, and *change agency* was its discipline of study. From Wolfensberger’s perspective, what was the point of human service activity if not to effect change?⁵²⁷ How can the US Catholic Church effect the change it calls for in the *US Pastoral Statement* regarding individuals with IDD, both inside the Church and in society? A good place to start would be doing so within, then it could become an authentic model to influence society. Such would be consistent with the intentions of the Second Vatican Council, for a renewal of the Church led by the Holy Spirit, so it could live out the gospel more faithfully and engage with the world on the problems of the day that undermine human dignity and flourishing and the objective outcome of the *US Pastoral Statement* that is woven throughout its text.⁵²⁸ Such a task is what Social Role Valorization is designed to facilitate and what I will present in the next chapter.

⁵²⁵ Wolfensberger, "An “If This, Then That” Formulation of Decisions Related to Social Role Valorization as a Better Way of Interpreting It to People," p. 460. His commitment to this issue is reflected in the name of the center at Syracuse University, the Training Institute for Human Service Planning, Leadership and Change Agency.

⁵²⁶ in *Merriam Webster.com Dictionary* (Springfield, MA: Merriam-Webster, Inc), s.v. “agency,” accessed June 3, 2020, <https://www.merriam-webster.com/dictionary/agency>.

⁵²⁷ Phone conversation between author and Robert Flynn, 5/9/2020. I really appreciate Flynn’s generosity of time, references and insights about Wolfensberger, his friend and colleague. As an aside for the current reference above and much to the purpose of this project, Flynn also shared that Wolfensberger considered the Church very poor at change agency, much to his chagrin.

⁵²⁸ Council Fathers of Vatican II, "Message to Humanity, Abbott," L 385-449.

VII. Extinguishing the *Shadow Narrative* with Social Role Valorization

“I have always known this: Life damages us, every one. We can’t escape that damage. But now, I am also learning this: We can be mended. We mend each other.”

~ Four, *Allegiant*, *Book of 3 Divergent Trilogy* by Veronica Roth

In the last chapter I presented *SRV* as the constructive framework to understand the marginalization of individuals with IDD caused by the *shadow narrative* in the US Catholic Church. Its tools will help elucidate marginalization dynamics and suggest counter strategies that promote operative narratives about persons with IDD as integral and valued members of the human family and the body of Christ. Responding to its criticisms reinforced *SRV*’s emphasis on the individual person to foster connections within community and enhance ability to participate meaningfully in valued roles within in a parish. In this chapter I will draw on its principles to guide choices for particular pastoral and community situations, including how to assess a plan’s integrity and outcomes. I will close with a summary proposal for the US Church.

The goals of *SRV* harmoniously support shifting focus from fitting persons with IDD into predefined spaces, as has been discussed throughout the text so far, thereby breaking down what Reynolds calls, the “cult of normalcy,” as discussed in chapter three. It provides empirically driven strategies that have been highly effective at the core of making individuals with IDD more meaningfully engaged within community life, such as in supported employment. Beyond that it’s compatibility with the task draws from Wolfensberger himself. Although it was developed to make a difference in the lives of persons with IDD in general, it works within any community setting. Wolfensberger saw its applicability to all faith traditions and he spoke and wrote quite prolifically on the subject, particularly for Christianity in general and the Catholic Church in particular,

since he was Catholic. Within the Church, he challenged clergy, religious, and lay people to assess how well the Church lived what it proclaimed.⁵²⁹

A. Diminishing Shadow Narrative and Countering Devaluation

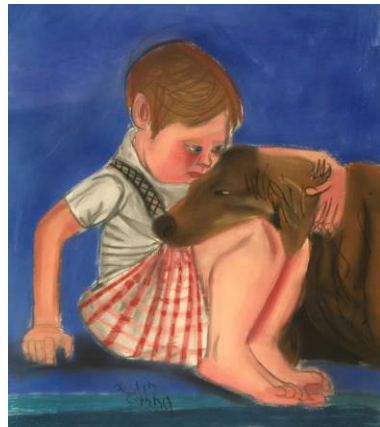
SRV maintains that the way to counter negative expectations about devalued persons is through positive, personal experiences. The more negative the association, the stronger the positive experience needs to be. This is one reason why education alone and meeting persons with IDD has not been helpful, particularly if the introduction occurred in awkward or uncomfortable environments.⁵³⁰ I did not know anyone with autism when I began working in this ministry. Stereotypes about individuals with autism say they are disconnected from others, and of lower intelligence. Though my head told me not to believe the stereotypes about them, my heart was engaged only through theological faith statements. In other words, not very deeply. Then I met Ben and Justin, and everything changed.

Ben was eight years-old at the time, and attended a school for students with autism. Mary Beth, his mother, had been taking him to mass since he was four, and when he was eight, he began attending the parish catechetical program to prepare for First Celebration of Eucharist. One Sunday Ben laid down across the pew during mass. Mary Beth only had to ask him once if he wanted to go to religious education that day, and his behavior was totally on task the rest of mass. Justin was in his late teens when I met him. He attended an inclusive public school with excellent supports for diverse student learning needs, yet, there is no mistaking that Justin has autism. Justin is also

⁵²⁹ Wolf Wolfensberger, "The Most Urgent Issues Facing Us as Christians Concerned with Handicapped Persons Today," *Journal of Religion, Disability & Health* 4, no. 2-3 (2001): p. 100. Originally presented at NAMRP conference in Denver, August 1983.

⁵³⁰ "A Contribution to the History of Normalization, with Primary Emphasis on the Establishment of Normalization in North America between 1967-19751," in *A Quarter-Century of Normalization and Social Role Valorization: Evolution and Impact*, ed. Robert J Flynn and Raymond Lemay (University of Ottawa Press, 1999), p. 54.

an artist. The picture below, *Child with Dog*, is my favorite, though I appreciate much of his art.



The common thread in the two stories about Ben and Justin is the evidence of awareness and interest in relationships and emotions. Ben was clearly motivated to go to religious education and be with his “typically developing” peers, and Justin is clearly aware of emotions and relationship, because this charcoal picture is Oozing with it. Yet the operative stereotype of individuals with autism is that they are not interested in other people, they are disconnected from others, totally tuned into themselves and their inner world. Meeting Ben and Justin, my heart became engaged in believing in the possibilities of persons with disabilities, as well as validating their interests in more than restricted, relegated spaces.⁵³¹

1. Relationships – Essence of Being Church

The personal connections and interactions with Ben and Justin provided me with two positive experience with two different individuals with autism. Changing perceptions and envisioning new possibilities about a person is where SRV comes in. It utilizes known pedagogies to enhance learning, develop new skills and provide opportunities to participate in new roles for individuals who have been devalued and marginalized.⁵³² This expects to increase the person’s possibilities for interactions with new people in the community, who witness their progress and development. It helps to then positively

⁵³¹ Webmaster, "About Justin Canha," <http://justincanha.com/about>.

⁵³² Lemay, "SRV on Social Integration Conundrum," pp. 1-10; Colleen McLaughlin, Richard Byers, and RP Vaughn, "Responding to Bullying among Children with Special Educational Needs and/or Disabilities," (London, UK: University of Cambridge 2010), pp. 38-51. A contemporary support for these principles, though without naming SRV specifically.

change expectations of them, as well as offer possibilities for new relationships.⁵³³

Pastoral leaders should first establish a relationship with the person, to get to know them and the important people in their lives. The goal is for the person to flourish within a network of relationships, rather than imposing random goals. I do not mean to imply that this is easy and that there will not be challenging times. But that is why relationship is so important, because when there is truly a relationship, then trust and respect can help you through the difficult times. And the way relationships are developed is by being together.

One example is Bob,⁵³⁴ a young man with autism who loved going to mass every week. He is 'heavily involved' on the autism spectrum as some would say. But he had participated in the complete parish catechetical program, was confirmed and continued to attend mass every week. He particularly enjoyed sitting by the choir. In his mid-twenties, Bob started evidencing some very challenging behaviors. Part of his routine was to shake hands with the celebrant at the end of mass on his way out of the church. He developed the tendency to do so by making a pushing palm plant on the presider's chest. Complicating the situation was the fact that the pastor had recently had open-heart surgery, which made him very uncomfortable with the situation. At the same time, he knew Bob meant him no harm. Further complications were that Bob had started having seizures, and was trying different medications. There were a number of other stressful situations the family was going through. A lot of time and effort went into trying to work through these new issues, but it did not always go smoothly.

One thing in particular that was quite impressive, though, was how members of the parish stepped in to help, without being asked. A man, who was a good size, began staying on alert so he could intercept Bob if he went for the pastor. One Sunday when Bob ran out of the church, a woman parishioner went after him to help his mother. Her

⁵³³ Wolfensberger, "A Brief Overview of Social Role Valorization," pp. 105-107, 116-122; The Keystone Institute, "An Introduction to Social Role Valorization: A Framework for Assisting People to Have Full, Rich and Meaningful Lives: A Comprehensive SRV Workshop."

⁵³⁴ Not his real name.

son had been with Bob all through religious education, so she knew him and his parents. These supports would not have happened without relationships, which requires long-term proximity, familiarity and trust. It exemplifies Wolfensberger's description of Christian *communality*, which overlaps integration, but does not equal it. Gifts and needs are mutually shared for the benefit of the group.⁵³⁵ Something more also unfolds from this communality, in the spaces "in between" as the Spirit is evidenced.

Ben's mother, Mary Beth Walsh is a theologian and peer-counselor for parents of individuals with disabilities. While I have already discussed the importance of valuing presence as much as active participation, Walsh relatedly notes there are some individuals whose profound disability is rooted in their very agency, their ability to move and act, without necessarily understanding the implications of their actions. The story above about Bob and his parish illustrates this. Specifically speaking of individuals who are profoundly affected by autism in "Autism, Culture, Church: From Disruption to Hope," Walsh raises tough questions for the Church to consider. She challenges all faith communities to become places

where individuals with autism are valued for who they are, where they are coached and taught and supported and encouraged to participate in a way that is meaningful to them and valued by the community. Houses of worship must become safe places. Questions that we cannot answer in theory, we can address in practice. ... but only if churches really commit themselves to seeing beyond the surface and listening for the voices that are hardest to hear.⁵³⁶

I share this example to demonstrate that it is not always going to be pretty or easy. But having relationships forms the foundation to work from. There is not a play book to handle every scenario, but it is truly amazing what can happen when people are open.

⁵³⁵ Wolfensberger, "The Most Urgent Issues Facing Us as Christians Concerned with Handicapped Persons Today," pp. 117-120. Amongst those who knew Wolfensberger, he was famous for his "Wolfisms." "Communality" is one for "communio."

⁵³⁶ Mary Beth Walsh, "Autism, Culture, Church: From Disruption to Hope," in *Living Fully 2016: Celebration of Disability, Culture, Practice and Faith* (Rome, Italy: The Pontifical Council For Culture and The Kairos Forum, 2016).

Bob's parish is one that truly values everyone and believes that everyone belongs. And they work hard at it, which means not avoiding difficulties. I will repeat what I said at the end of chapter 5. How can the Church do this? It will require attention to the tensions between individuals and the whole. It will also require trust in the presence of the Spirit animating this process to continually work toward increased comfort and openness that can lead to unfolding possibilities, rather than simply reinforcing what is familiar and therefore more comfortable. Natural relationships, friendships, are elusive for persons with IDD. Reinders' *Receiving the Gift of Friendship* is considered the classic text on this subject.⁵³⁷ Given the communal identity of the Church, it would seem to be a perfect space to not only allow, but to encourage such developments. Two variables are particularly important for their development, which I will briefly discuss next, proximity and strengths.

a. Physical Proximity and Relationship

Physical proximity is important, but alone is insufficient. There needs to be opportunities for interaction, ideally within natural settings, rather than artificial ones. So rather than setting up an event for "typically developing" individuals to do something with individuals with IDD, it is much more productive to take advantage of mutual interests that allow individuals with disabilities to share particular experiences, interests and abilities with peers.⁵³⁸ One example is a pastor who sought to help a man with IDD get to know more people in the congregation and developed a Sunday afternoon football club. The man enjoyed watching football, was quite an enthusiast, so everyone who enjoyed watching football was invited to come to the rectory. Of course, food and beverages were part of the experience, as in any football gathering, and relationships

⁵³⁷ Reinders, *Receiving the Gift of Friendship*.

⁵³⁸ Lemay, "SRV on Social Integration Conundrum," 3-8. Peers here refers to individuals of same or similar age and mixed abilities, with and without disabilities.

evolved out of the group.⁵³⁹ Relationships are an important part of life, in and of themselves, but we also grow through our relationships as well.

b. Strengths vs. Deficits

Another example comes from a youth minister in the Archdiocese of Albany. Two teens with autism were ostracized in the program. They had proximity, but as noted above, it was not enough. After some deliberation, the team thought to determine what particular each of the two teens were particularly good at. One was a master at video games and the other at model car racing. The team planned events in which each would lead an activity based on these strengths. It was vastly successful, and facilitated relationships that spilled into the teens' school and social lives. This highlights another important point, focus on strengths not deficits. It is also more successful to do this in smaller groups, to promote interpersonal identification and promotes a sense of responsibility for each other.⁵⁴⁰

B. Principles for Guiding Choices

Positively changing expectations of vulnerable individuals happens through intentional, supportive practices; getting to know the person, their interests, hopes, dreams, and frustrations. The essential task in setting up a pastoral plan according to SRV is to maximize positive impressions of the individual on people in the congregation and to minimize risks of negative impressions.

1. Typical and Ordinary Ways – Culturally Valued Analogue

First impressions are powerful, especially if it reinforces negative expectations, which only raises the stakes for a positive outcome the next time. Careful attention to

⁵³⁹ Institute on Theology and Disability, "Unpublished, Bill Sharing Stories During Conference Conversation," ed. Bill Gaventa (Holland, MI, 2016).

⁵⁴⁰ The Keystone Institute, "An Introduction to Social Role Valorization: A Framework for Assisting People to Have Full, Rich and Meaningful Lives: A Comprehensive SRV Workshop."; Carter et al., "Known for My Strengths: Positive Traits of Transition-Age Youth with Intellectual Disability and/or Autism."

detail is important, to prevent this, considering what is typical and valued for other individuals of the same age, gender and cultural context, which is known as the *culturally valued analogue* (CVA).⁵⁴¹ Through working with the individual, as well as some family and/or friends, a list of ideas are generated, as well as what supports are necessary for successful participation.

Cognizant of the potential negative consequences, *SRV* attends to typical ways of doing things in society that incorporate its mindsets and values, while seeking to discover unconscious biases. It also factors a person's social capital, which refers to the "currency" one has to spend in social situations, what Reynolds refers to as body capital, discussed in Chapter Two. The higher someone's social status, the more currency they can spend on counter cultural actions and options. Although *SRV* considers normative practices and roles in the community, its purpose is not to impose goals and expectations on devalued individuals. It seeks to equip them to navigate the world that *is*, believing that people can grow, learn and stretch with appropriate understanding, support, and respect.⁵⁴²

David initially filled a typical role in the parish catechetical program, but this was based on his natural strengths of friendliness and an amazing memory. Later, he developed his own unique place representing the voices of their sons and daughters of the parent groups' members. As people in the congregation see persons with IDD participating in unexpected ways, *SRV* says their expectations will change, one person at a time. This can open possibilities for the light of the Gospel to shine and extinguish the *shadow narrative*, one person at a time. *SRV* focuses on developing roles in typical

⁵⁴¹ Milton S Tyree, Michael J Kendrick, and Sandra Block, "Strengthening the Role of the Employee: An Analysis of Supported Employment Using Social Role Valorization Theory," *Journal of Vocational Rehabilitation* 35, no. 3 (2011): p. 200.

⁵⁴² Pontifical Council for Justice and Peace, "Compendium of Social Doctrine," par. 148, 151, 164-166, 171-184, 185-188, 192-196. Such is consistent with Catholic social doctrine concerned with the common good, subsidiarity and solidarity, three overarching themes all based on human dignity.

and ordinary ways as a conduit to developing natural relationships. Within the Church, this provides access within which the Spirit can work.

Focusing on what is typical is important, because “‘special’ activities drive out the ordinary” and reinforces differentness.⁵⁴³ The practice of “segregating and congregating” groups individuals with IDD together based on the arbitrary category of intelligence, which precludes opportunities for interaction, developing relationships, modeling and learning within the body of Christ. Such practice undermines the ontologically defined diversity within unity St. Paul notes and Catholic Social Teaching reinforces. The social nature of individuals is diverse, which the common good depends on.⁵⁴⁴ Segregated and congregated groupings distorts community demographics, which taxes the community’s ability to provide natural supports.⁵⁴⁵ When diversity and openness are valued within the body of Christ, SRV can work for people to participate in roles that build on their strengths, or at least where challenges can be considered advantages, and that will be valued within the community.

A helpful illustration comes from a supported employment example, which SRV theory informs significantly, as well as community inclusion work. A young man we’ll call, Dave, likes to be active, has some marketable skills, and also has IDD. However, Dave also had terrible hygiene. Neither family nor job coach could convince him to develop it, no matter how hard they tried. Then someone new got involved and flipped the focus. Rather than trying to change Dave on matters of hygiene, which had gone nowhere, they looked for jobs in which it would not matter. They found a tire destruction

⁵⁴³ The Keystone Institute, "An Introduction to Social Role Valorization: A Framework for Assisting People to Have Full, Rich and Meaningful Lives: A Comprehensive SRV Workshop." Day 3.

⁵⁴⁴ Pontifical Council for Justice and Peace, "Compendium of Social Doctrine," par. 151.

⁵⁴⁵ Wolfensberger, Thomas, and Caruso, "Some of the Universal “Good Things of Life” Which the Implementation of Social Role Valorization Can Be Expected to Make More Accessible to Devalued People."; Wolfensberger, "A Brief Overview of Social Role Valorization."; "Attempt toward Theology."

facility, which already had plenty of bad smells, so Dave's fragrance was not a problem. He is a good worker, made friends, and was quite happy, continuing to ignore issues of hygiene. Then one day his co-workers wanted to meet at a bar, after going home to shower and change. They invited Dave, who wanted to just meet them there as he was. However, his work buddies were clear that was unacceptable. If he remained as he was, he would scare women away they said. So, Dave went home, showered, changed and met them at the bar and hygiene was no longer an issue.⁵⁴⁶ This does not mean that in congregational life the goal would be to change someone, to get them to improve their hygiene. However, the example demonstrates that stigmatizing behavior may decrease as acceptance in other areas increases, which in itself, is a notable observation.⁵⁴⁷

Essentially, the goal is to consider where someone's gifts can shine, where challenges become an asset, or at least neutral, as in the case of David above. Another example is Rick⁵⁴⁸, a young man who struggled with significant social anxiety. He was withdrawing from all social interaction, though he would go to mass. His father approached their pastor for help, who connected him with the youth minister. She talked with Rick and learned that he really enjoys photography and videography, so she asked if he would like to be the photographer for some special events they had at the parish, which he did. After doing that for a few months, Rick also began recording the Saturday evening liturgy, which was broadcast on a local television channel on Sunday morning, connecting people who could not go out of their homes with the worship community, at least remotely.

⁵⁴⁶ The Boggs Center on Developmental Disabilities, "Employment Specialist Foundations Course." Day 3: "Job Coaching Phase." Example shared by course instructor, Bethany Chase, LSW. October 18, 2019.

⁵⁴⁷ Amado, "Community Building, Friendships and Social Relationships," p. 115; "Building Relationships between Adults with Intellectual Disabilities and Community Members: Strategies, Art, and Policy."

⁵⁴⁸ Not his real name

Rick not only enjoyed serving as the parish photographer and videographer, but serving in this role has helped his confidence grow to the point he felt comfortable to engage in the world again. He is now taking classes in media and videography and wants to pursue it as a career. After some time has passed, Rick has a job in his chosen profession. He continues to be the videographer for the parish mass that is broadcast on Sunday mornings for people who cannot leave their home, but he is no longer paid for his work, at his insistence. The pastor was initially uncomfortable about this, but Rick was adamant. It is his contribution to the parish. Remember, one of the good things in life is to contribute, to feel needed.

Another striking example that illustrates focusing on typical and ordinary ways is a story from Cindi Swanson, a social worker who works with congregations on inclusive practices in Illinois, that she calls "I Came for the Juice Boxes and Stayed for the Soul Food."⁵⁴⁹ Cindi worked on a support plan with the mother of Sammy a six-year-old boy with autism. After the first day, she called Cindi at home and insisted it would not work, she would work with him at home. However, Cindi would not let that happen, she kept asking what was positive about the session, there had to be something. Finally, Sammy's mother said, "okay, the juice boxes, he liked the juice boxes!" "Great," said Cindi, "he will be the juice box distributor at the beginning of religious education!"

The other thing that they included in the plan was to increase the amount of time that Steven would be there. Ninety minutes was too long, so they started with the first 10 minutes and gradually increased the time, so things were always ending on a good note. Sammy enjoyed going and he was part of the group, he belonged. But this is not the end of the story. During the summer, when religious education does not meet, Sammy, his sister and mother went out for ice cream. But something spooked him in the ice cream shop, and he bolted out the door and ran down the street. As his mother was running after him, to try and catch him, another set of footsteps passed her. Sammy had made it to their car and got inside. The other set of footsteps were those of Jeffrey,

⁵⁴⁹ Cindi Swanson, "I Came for the Juice Boxes and Stayed for the Soul Food," (in person: conversation with author, April 2016).

another boy in Sammy's religious ed group. He followed Sammy into the car, sat close to him and stroked his knee, speaking soothingly to him as he did it. No one could have expected such an outcome after Sammy's first day experience at religious education. But because he was there with the kids, and he had a role that was appreciated, Sammy had relationships in the community, and he was valued.

2. *Conservativism Corollary*

The list of possibilities are then assessed for risk factors to enhance or further marginalize the person, which is referred to as the *conservatism corollary* (CC).⁵⁵⁰ Options that maximize positive potential are prioritized over less potent ones, because it recognizes that socially devalued people live in heightened vulnerability. The same choice will impact people in different ways, based on their valued status within the community. However, it is not about taking things away; it is about adding and explaining options. For example, Bill, a 22-year-old man with Down Syndrome, wanted to wear a Mickey Mouse t-shirt to his job as a construction worker. Given the tendency to see individuals with Down Syndrome as perpetual children, wearing the t-shirt will most likely reinforce this perception, even though a 'typically developing' 22-year-old does not share this risk. However, the process includes respectfully discussing these implications with Bill, which respects his ability to learn and develop awareness about the implications of choice.

The example of Bill's experience has significant implications for his desire to be seen as an adult and a respected peer by his co-workers. One could reasonably argue that peers within a congregation should look beyond such things as mickey mouse t-shirts. Yet, the power of subconscious attitudes will exact a cost for a person who is vulnerable to being seen as an eternal child. Further, does that mean Bill should not be encouraged to think about the implications of what clothes he chooses to wear when doing something with the young adult group or attending liturgy? Not doing so disrespects Bill's own' expressed desire to be taken seriously, as an adult.

⁵⁵⁰ Tyree, Kendrick, and Block, "Strengthening the Role of the Employee: An Analysis of Supported Employment Using Social Role Valorization Theory," p. 204-205.

Although children are often allowed more flexibility when considering what is typical, there is reason to be cautious with this, no matter how well intentioned. People may think it is compassionate to tolerate a cute little five-year-old running up the aisle and around the sanctuary during mass. However, they will not be so forgiving when he is 16, weighs 250 pounds, and sits on the lap of an elderly parishioner.⁵⁵¹ To use Wolfensberger's language, "communality," does not mean that "anything goes. Not only are the person's interest, needs and abilities important, but the needs of the community are as well."⁵⁵²

It is more than just an issue, however, about tolerating inappropriate behavior. "Indeed," Wolfensberger says, "it is part of the good life to be surrounded by people who have positive growth expectations for one, and a commitment to help one grow... [with] a delicate balance among developmental challenge, kindness, and spiritual nature in order to unfold their talents and spirituality and if they are Christians, to practice their charismatic gifts."⁵⁵³ It is much easier for a five year old to learn how to act during mass and other community events, than it is to unlearn 16 years of inappropriate but tolerated behavior. More importantly, however, is the dismissive assumption that the five-year-old child with autism cannot learn to act differently. Low expectations deny the person's ability to learn and diminish their potential development. So, tolerating the behavior, such as running around the church during mass, is *not* a Christian response.

3. Natural and Smaller Over Efficient and Larger

Social Role Valorization prioritizes informal and natural networks of relationships over developed supplemental programs. This not only reflects its developmental

⁵⁵¹ Pam Louwagie and Curt Brown, "Accommodating Autism: Where's the Fine Line," *Star Tribune*, April 6, 2011 2011.

⁵⁵² Thomas, "Historical Background and Evolution of Normalization-Related and Social Role Valorization-Related Training," p. 371; Lemay, "SRV on Social Integration Conundrum," pp. 6-10; Wolfensberger, "Social Role Valorization: A Proposed New Term for the Principle of Normalization," p. 439.

⁵⁵³ "The Good Life for Mentally Retarded Persons," p. 108.

framework connected to natural rhythms of identity formation and relationship development, but also a concern with the integrity of programs. Wolfensberger was adamant about not only reduced benefits, but about the increased possibility for undermining purpose, as well as possibilities for abuse and neglect.⁵⁵⁴ Not only isolating, their purpose is typically to be more “efficient,” yet the efficiency is concerned with either “content of faith” in a catechetical program or managing people for other types of programs and activities. Not only does this preclude diversity and richness of experiences for everyone, it constricts persons with disabilities into flat environments and also leaves the community at large without any demands to change.

Some service programs may prioritize continued dependency on the agency over a person’s diminished need for it.⁵⁵⁵ This can happen for different reasons, such as agency fiscal needs, or schedule impact on family life. Within the body of Christ, this has no place. Wolfensberger challenged “imperial services super-system” and strongly advocates more informal communalities, personal relationships and advocacy. He also encouraged the development of intentional parishes, “radical Christian congregations” in which a community serves and meets the needs of its members. Disproportionately large numbers of individuals with disabilities in one congregation would overwhelm a community’s ability to meet their needs and it would diminish true communality.⁵⁵⁶ As such, SRV provides a practical framework to incarnate Christian charity that prioritizes natural relationships over institutional ones, without dismissing their importance, as we discussed earlier in the chapter on charity, and also echoes the *US Pastoral Statement*.⁵⁵⁷ Acts of authentic charity seek to meet the needs of the person, even

⁵⁵⁴ "The Most Urgent Issues Facing Us as Christians Concerned with Handicapped Persons Today," pp. 99-102.

⁵⁵⁵ "Prophetic Voice and Presence," pp. 37, 38.

⁵⁵⁶ "The Most Urgent Issues Facing Us as Christians Concerned with Handicapped Persons Today," p. 102; "The Normative Lack of Christian Communality in Local Congregations as the Central Obstacle to a Proper Relationship with Needy Members," pp. 117-118.

⁵⁵⁷ Pope Benedict XVI, *Caritas in Veritate (Charity in Truth)*. par. 11.

when it's hard or incompatible with personal preference. For example, a parish catechetical leader working to support integrated participation in the catechetical program of different individuals with disabilities with their same aged peers, rather than setting up a separate program, mixing a wide range of ages. The integrated participation with same age peers increases the opportunities for interaction and possibilities for relationships, learning new skills and abilities through modeling and opportunities for practice. In short, concern for the whole person. This is only one example that Bishop Costello was thinking of when he suggested the prophetic vision of natural relationships within the Church minimizing the need for institutions and paid supports.

3. *Model (Pastoral) Coherency*

Model coherency, which I note as *pastoral coherency*, refers to the process that assesses the integrity of a support plan based on the relationship between its three components. The first assumptions are *about who is served and what their needs are*. The second assumptions are about what will be provided based on the needs identified. The third set of assumptions concern the methodology of how the support will be provided. The methodology includes assessing appropriateness of method, if utilizing natural relationships and/or supplemental programs, the backgrounds and identities of supportive people, the appropriateness of setting, language used about services and people, etc. It is important for the assessment to be made according to the principles of SRV. Its purpose is to test for disconnects regarding who or what the plan is serving. Is it providing more support for the needs or desires of a caregiver or service provider, or the person with IDD? For example, respite for parents is a worthy pastoral practice, unless it is done in ways that diminishes the person with IDD. Examples of this are activities that are not age appropriate, respectful of interests or stigmatizes in some way. In fact, when parent respite is the focus, developmental goals for their sons and daughters can be undermined. Alternatively, when the focus is development rather than service, there is the realization that all relationships benefit from time together and time

apart.⁵⁵⁸ “Real respite occurs as a by-product, a natural consequence of engaging in activities with others inside and outside the home.”⁵⁵⁹

There is another dimension of *pastoral coherency* that is more nuanced and is related to the next point, preparing the community. The *conservatism corollary* stipulates planning for maximum positive effect, as already noted. In my conversations with Susan Thomas and Robert Flynn, they both emphasized that Wolfensberger was also a realist who wanted to promote change. So although the goal was the ‘best good,’ sometimes the best choice would be to determine the ‘least bad.’⁵⁶⁰ This reminds me of the references in the *US Pastoral Statement* and other US Bishops documents to “as best as possible” and other related phrases. Perhaps this is where the bishops got that from. I will say the bishops probably intended to positively frame Wolfensberger’s language.

Alternatively, I have always advised parish pastoral leaders to begin where they are, but to always be working toward higher levels of interaction and participation.⁵⁶¹ Wolfensberger’s phrase, ‘least bad’ similarly acknowledges improvement is still needed and to be worked for, whereas ‘as best as possible’ could imply this is as good as can be expected. The dilemma, as I discussed earlier, is that often in pastoral situations, “as best as possible” is very subjective and the latter interpretation is what I typically observe in such instances. So, I still maintain it feeds the *slippery slope of idealism*

⁵⁵⁸ John Armstrong and Lynda Shevellar, "Re-Thinking Respite," *The SRV Journal* 1, no. 1 (2006): pp. 16-24.

⁵⁵⁹ *Ibid.*, p. 22.

⁵⁶⁰ Robert J Flynn, "A Conversation About Wolf Wolfensberger," ed. Anne Masters (telephone: conversation with author, 5/9/2020); Susan Thomas, "A Conversation About Wolf Wolfensberger," (phone conversation: conversation with author, 5/12/2020).

⁵⁶¹ Anne Masters, *Pastoral Ministry with Persons with Disabilities Parish Resource Guide* (Newark, NJ: The Advocate, 2013), pp. 38-39; I drew from: Linda Meyer, "Inclusion for Individuals with ASD Throughout the Lifespan," ed. COSAC (Caldwell College, West Caldwell, NJ 2006). Meyer drew from W.L. Heward's *Contium of Models*, 2003.

within the *shadow narrative*, even though it may have initially been intended to encourage beginning where possible. In reality it is often interpreted to sanction incomplete action and support.

4. *Preparing the Community*

Preparing for positive possibilities, “share[ing] so people can hear,” and facilitating connections are critical considerations for success. Proximity alone doesn’t make positive associations, and they can be negative if poorly planned. But also, preparing the community is important part of supporting the process. Acceptance of individuals within roles comes from the community. Without proper preparation, not only is the community not respected as a partner in the process, it is apt to feel put upon or called to “engage in a fiction.”⁵⁶² Wolfensberger says the community needs to resolve to be a communality before initiating any plans or strategies. If it is forced without that, it could be very difficult if not impossible to develop. Alternatively, however, if community resolution is first, and therefore communality is desired, he says there may be little need for strategies and plans at all.⁵⁶³

When thinking of a particular person rather than globally, remember the purpose, which is to facilitate meaningful participation and sense of belonging of someone who has been marginalized. There is another reason to prepare the community intrinsic to SRV. Think of how anyone would typically be introduced into a parish community, welcomed, embraced and assisted with making connections that can lead to relationships. There needs to be an introduction, and also it would be very usual to identify possible candidates from within the community to assist in the process. Typical

⁵⁶² Lemay, "SRV on Social Integration Conundrum," pp. 6-12; Thomas, "Historical Background and Evolution of Normalization-Related and Social Role Valorization-Related Training," p. 371; Wolfensberger, "Social Role Valorization: A Proposed New Term for the Principle of Normalization," p. 439.

⁵⁶³ "The Normative Lack of Christian Communality in Local Congregations as the Central Obstacle to a Proper Relationship with Needy Members," p. 119.

patterns of introducing someone within a community should be followed, including preparing and working with the community.⁵⁶⁴

5. *Implications of Choices*

As indicated at the end of the last chapter, effecting change was the essential object of SRV, and Wolfensberger believed it was critical that people realize there are consequences for both actions taken and not taken.⁵⁶⁵ He used logic formulations to provide context for the decisions to be made based on expected consequences for different options. SRV draws from empirical studies on social relationships and service systems to provide what Wolfensberger called an “overarching meta-theory” to guide this process based on expected outcomes.⁵⁶⁶ Plans intended to enhance someone’s image and competency within the community should be developed based on respectful attention for the particular individual’s goals, interests and contextual variables and the parish culture and mindset.

If X is done, then one must expect Y will occur. Recalling the example of Bill wanting to wear a Disney shirt to work, if Bill wants to be respected as a 24-year-old co-worker, choosing a shirt that a “typical” 24 year old would wear will increase his chances, and diminish possibilities that his co-workers will see him as a child, which is a particular vulnerability for adults with Down Syndrome. Alternatively stated, if Bill chooses to wear the Disney shirt, the chances increase that his peers will continue to see him as immature, and decrease the chances that they take him seriously as a peer.

Conversely, Wolfensberger says, if Y has occurred, most likely X happened. For an example within the Church, if you say individuals with IDD do not sin and are in a

⁵⁶⁴ Lemay, "SRV on Social Integration Conundrum," p. 12.

⁵⁶⁵ Wolfensberger, "An “If This, Then That” Formulation of Decisions Related to Social Role Valorization as a Better Way of Interpreting It to People," p. 460. His commitment to this issue is reflected in the name of the center at Syracuse University, the Training Institute for Human Service Planning, Leadership and Change Agency.

⁵⁶⁶ Ibid., pp. 456-457.

perpetual state of grace, you can expect that they will either be present in stereotypic ways or not be very visibly engaged in congregational life. Congregations will not work out supportive strategies for typical and usual participation, because there is the assumption that they do not have need for ongoing sanctification, as everyone else does. Similarly, saying that ‘their’ presence brings out the best in people, may provide motivation for certain levels of support, which demonstrate ones ‘better nature,’ but it will not encourage authentic interaction and relationships, because the focus is on ‘doing for’ the person and the “doer” becoming a better person or demonstrating their virtue. Here some adults with IDD may be visible in roles typically performed by children, such as an altar server. It is fine if the adult really wants to continue as an altar server. It is problematic when no other options are available or suggested. In other words, if there is not ongoing engagement. Separate programs and events for individuals with IDD feed into this as well. The people involved typically mean well, but as already noted, maintaining separate structures reinforces difference, undermines development and minimizes opportunities for authentic interaction and encounter.

Using Wolfensberger’s logic formulation, if the Church believes that everyone belongs and the body of Christ is only complete when everyone is participating within the community, then the parish will develop pastoral support strategies which assume the person can participate, and assess and reassess as necessary. This cannot be done based on stereotypes and generalizations, such as ‘people with autism’ or the ‘Downs kid.’⁵⁶⁷ Ben, already introduced, is a young man with autism who has been

⁵⁶⁷ Kristoffersen, "Life Story Work: An Important, but Overlooked, Instrument."; Meininger, "Narrating, Writing, Reading: Life Story Work as an Aid to (Self) Advocacy," p. 187.; Clarke, Jane Hanson, and Ross, "Seeing the Person Behind the Patient: Enhancing the Care of Older People Using a Biographical Approach." Life Story Work is a process used in gathering illustrations, stories and narratives of a person’s life to empower and see beyond the diagnosis have also been shown to facilitate relationships between the service provider, the person receiving services and his/her family, as well as fostering self-awareness and self-advocacy. Though initially used primarily with persons with dementia, there have been many endorsements of applying the same principals to facilitating relationship and nurturing meaningful participation for individuals with I/DD.

attending mass since he was four. The parish developed a pastoral plan based on the above assumptions and values, working with his family, teachers and peers to develop a pastoral plan, as well as Ben when he was able to. He participated in the parish religious education program through confirmation and continues to be an active participant in the congregation. Throughout the years the plan was adapted based on Ben's changing needs and the different contexts through a concerted effort that included the relevant people mentioned above.

Recalling the principles of *SRV* the initial secondary role for Ben within the parish is that of parishioner, which potentially initiates a number of additional roles, the first of which was learner in the parish catechetical program. With the initial role of parishioner identified, his family worked with pastoral leaders, peers in the parish, and teachers from school to establish ways for Ben to participate in Mass and religious education. This facilitated opportunities of engagement with 'typically developing' peers and the worship community in positive ways that have reshaped expectations of Ben in particular and of individuals with autism in general. However, it did not stop there. Through the years Ben's participation has developed within additional roles in the parish, such as greeter, and preparing the Gifts Table before Mass. These roles evolved through his interaction with other parishioners involved in ministry, not necessarily pastoral leaders, which highlights the importance and benefits of proximity and natural interactions.

SRV provides principles that may be used to take action. But, the goals of the plan are based on the values of the community, which are beyond *SRV*'s scope. The goal to support Ben's participation came from the Church's values, while the how was supplied by principles of *SRV*, identifying what roles Ben and his family were interested in for him, and then identifying appropriate ways to proceed. Ben's family ensured that he developed the skills necessary to participate in community events, including mass. They developed a plan with the parish that included peer supports and a teenage mentor, as well as adaptations for expectations within the parish catechetical program. Recalling Matthews work on the two different ways of active presence, the logic equation on pastoral support for Anna was the same as for Ben, if the Church believes that everyone belongs, and the body of Christ is only complete when everyone is

participating within the community, then the parish will develop a pastoral support plan which assumes that Anna can participate, and assess and reassess as necessary.

The Church as the body of Christ is called to receive each other in love, just as we have each received the unmerited gift of love from God. Again, considering Wolfensberger's logic formulation, what are the implications of the Church's narrative about the human person before God? As the Church reconsiders the narratives told about individuals with IDD, it seems proper to also evaluate this. SRV would suggest that if individuals with disabilities are not within it, then recognition of their innate dignity and value is missing. This is a natural progression of the conversation, to at least briefly consider possibilities for the Church to move out from under the *shadow narrative* with a theological anthropology that reflects the diversity of the human family.

C. Narratives About the Human Person in the Body of Christ

How does the Church describe who humanity is before God, inclusive of all human persons? If it truly values the innate dignity of every person and believes that disability is an ordinary part of what it means to be human, rather than a tragedy to be suffered through or fixed, then its theological anthropology needs to reflect this. Remember that David Perry wondered about this very question in the discussion of charity in chapter four.

The Church says that each person is made in the image of God who is love, and that each is called to reflect this love into the world through the details of one's life. But what does this love look like? What is the movie frame or text that narrates it? Christian theological anthropology has been heavily influenced by cultural norms, historically privileging the experiences of white, Euro-American, socially entitled men.⁵⁶⁸ This is replete with boundaries that declare what it means to be human and fences out anyone who does not match.

⁵⁶⁸ Mary Doak, "Sex, Race, and Culture: Constructing Theological Anthropology for the Twenty-First Century," *Theological Studies* 80, no. 3 (2019): pp. 508-529.

Hans Reinders rightly points to the problems this presents to Christians, and further notes the concerns implicit in disability rights language and activities focused on inclusion. While stating intent to promote flourishing and participation, it apparently aims at overcoming disability, implying it should not exist. There are specific implications for the Church to attend the importance of reevaluating the narrative advanced by its theological anthropology. There are remnants of the *shadow narrative* that continue to be unquestioningly incorporated into new ecclesial texts, thus extending its life. Statements regarding individuals with disability need to be reassessed for their validity based on the test of the 'growing end' of understanding about persons with disabilities. This is not a matter of political correctness. This is a matter of texts that are decades to centuries old which have not been reassessed for the biases from the time and/or person they come from.

1. Some Enduring Tentacles of Shadow Narrative that Influence Catholic Social Teaching

I will share examples from two collective Church documents to illustrate the issue. The *Compendium of the Social Doctrine of the Church* is a solid compilation of Catholic social teaching that covers the full spectrum of social issues. It is well organized and indexed. Persons with disabilities are affirmed fully as subjects who have rights and responsibilities. However, this is "in spite of the limitations and sufferings affecting their bodies and faculties, they point up more clearly the dignity and greatness of man" it draws from *Laborum Exercens*, already discussed in chapter three.⁵⁶⁹ The concern is that the *Compendium*, which was published in 2004, utilizes text from 1981 that reinforces threads of the *shadow narrative* which devalues individuals with IDD because it promotes their identification with suffering and connection to the crucified Christ.

⁵⁶⁹ Pontifical Council for Justice and Peace, "Compendium of Social Doctrine," par 148. Quoting Pope John Paul II in *Laborem Exercens*, 22, as already discussed in ch. 3.

The other document is the *Directory for Catechesis* published very recently and I will share three quotes from it. While containing positive points, it claims that “persons with disabilities are a growth opportunity for the ecclesial community, which by their presence is prompted to overcome cultural prejudices.” It clearly draws from the *US Pastoral Statement* regarding prejudice without referencing it. More importantly, however, it takes the US bishops’ cautions about prejudices out of context and uses it to indicate the instrumental value of individuals with disabilities for the community. Later in the paragraph, though it calls for reciprocity and solidarity, the text also implies individuals with disabilities can ‘help the baptized interpret the mystery of human suffering.’⁵⁷⁰ Further building on the imagery of disability and suffering, the next paragraph ends by affirming “the openness to life of these families is a witness that deserves great respect and admiration.”⁵⁷¹ The document is drawing from the problematic text in *Amoris Laetitia* that was already discussed in chapter four on charity. The more troublesome issue I see is that Francis has adjusted his thinking regarding suffering and persons with disabilities, yet a significant work of Church teaching has missed his conversion and the larger conversation on disability and theology and memorialized it within Church teaching that has far reaching implications.

The other example also already identified in chapter three that refers to individuals with IDD as perpetual children or objects of pity. Though positively oriented to ensure access to the Eucharist, it is unfortunate that the Council’s best argument presumes individuals with IDD cannot sufficiently understand Jesus’ presence in the Eucharist, and therefore need to rely on the understanding of their family and community.⁵⁷² It is sourced in the *Propositio*, which locates intellectual disability within

⁵⁷⁰ Pontifical Council for the Promotion of the New Evangelization, "Catechesis 2020," par 270.

⁵⁷¹ Ibid., par 271. Drawing from Pope Francis, *Amoris Laetitia*, par. 47.

⁵⁷² Pope Benedict XVI, "Sacramentum Caritatis," par 178.

sickness that is suffered, and thus reinforces imaging of individuals with IDD as objects of pity.⁵⁷³

2. Some Thoughts for a Renewed Theological Anthropology

As has been discussed throughout this thesis, narratives build powerful associations that are based on particular mindsets and they influence peoples' lives in real ways, for better or worse. Recall the powerful change in mindset for Amy Julia Becker when she stopped seeing Penny as "her daughter with Down Syndrome" but as "just Penny." It shifted everything from worrying about what she wasn't doing to appreciating the wonder of her daughter and what she could do. Importantly, this includes expecting her to learn, but following Penny's lead rather than trying to meet uninformed expectations. A theological anthropology infused with the renewed understanding of the body of Christ presented in which the full diversity of humanity is represented seems appropriate. Such would suggest that the glory of God is revealed in the life of a flourishing human being, which is the possibility for everyone, each in their own way.

Reinders proposes that starting from a theology of creation, the question can be reframed as who each person is before God and, "[how to] understand disability experience at least potentially contributes to the goodness of life?"⁵⁷⁴ Rather than avoiding disability in favor of assimilation into a normative homogeneous anthropology, Reinders appeals to an ecological framework that promotes the flourishing of all creation, as constitutive of what it means to be human.

Characteristics that differentiate people, such as race, gender, ability, disability, etc. create boundaries that are often used to set up barriers between peoples. Such boundaries often cause tensions within communities. However, as the body of Christ,

⁵⁷³ Vatican News, "Synodus Episcoporum Bulletin Xi Ordinary General Assembly," par. 44.

⁵⁷⁴ Hans S. Reinders, "Understanding Humanity and Disability: Probing an Ecological Perspective," *Studies in Christian Ethics* 26, no. 1 (2013): pp. 38-44.

which acknowledges the diversity of the human family that was created by God, these boundaries should be embraced, rather than avoided. The Spirit is active within a community that reaches out and engages with those who are perceived as different, rather than avoiding such tensions. The Church is supposed to be the location of ongoing conversion and formation, which is a task of the entire community.⁵⁷⁵

Working through such tensions provides opportunities for growth and renewal, revealing new possibilities never expected. In this way new gifts can be discovered or provided the opportunity to develop and unfold. Such a communality values difference, as evidenced by a pastor saying, "When I hear someone shout out during mass, we're hearing God in another voice. It shakes things up a bit, which is good, because we can be so sterile sometimes. This is God's house, not my house."⁵⁷⁶ This parish values difference, and makes room for the manifestations of the Spirit to unfold as it will, in the spaces in between, where all are gathered.

The interconnectedness of humanity is at the center of Catholic Social Teaching with concern for the common good and solidarity, which extends to all creation. Karl Rahner suggests that we are essentially an open system, to be in communion with all of creation, in this "common sphere of living."⁵⁷⁷ When opening oneself to 'the Other,' the Mystery of God, one necessarily opens oneself to the 'other' who is neighbor, and this expands to include all creation. Such is advanced by Pope Francis in his encyclical *Laudato Si* as well.⁵⁷⁸ Rahner says that the history of 'love of neighbor' is unfolding in Christian consciousness and we must continue to be open to new insights based on the

⁵⁷⁵ USCCB, *NDC*, par 19.

⁵⁷⁶ Anne Masters, "All Are Welcome: A Call for Greater Recognition and Participation of Persons with Disabilities in the Church," *New Jersey Catholic*, June 2018, p. 16. Quoting Fr. Jim Worth, pastor of St. Joseph Church in Maplewood, NJ.

⁵⁷⁷ Karl Rahner, "The Body in the Order of Salvation," *Theological investigations* 17 (1981): pp. 87-88.

⁵⁷⁸ Pope Francis, *Laudato Si* (on Care for Our Common Home), (Brooklyn: Melville House Publishing: Libreria Editrice Vaticana, 2015). par 66.

Gospel and tradition.⁵⁷⁹ Essentially, Rahner indicates the importance of ongoing openness to the promptings of the Spirit to remain faithful to the Gospel. This unfolding is part of the 'growing end' of Tradition that brings together concern for human dignity and its implications for Christian charity.

Mary Doak offers some helpful insights into this conversation. Citing Rahner, she reminds us of the function of gratuitous grace to facilitate transformations within our world. Rather than avoiding boundaries in search of more homogeneousness, she argues for the importance to embrace the many boundaries found in human embodiment, gender, race, ethnicity, ability, disability, age, etc. Hidden assumptions of superiority need to be avoided, but it needs to be authentic.⁵⁸⁰ Doak's words concur that the Church is a natural space for engagement, participation and belonging for all persons, inclusive of those who have been marginalized, affirming the diversity of what it means to be human.

If a truly human life is one lived in communities enriched by and supportive of the diversity that is integral to humanity, then this ongoing work in theological anthropology has much to contribute to overcoming the tribal divisions and the growing individualism that distort not only society but also the church.⁵⁸¹

Doak offers potent implications to consider in updating the Church's theological anthropology. By embracing boundaries sincerely, the Church would open itself to the possibilities of grace-filled transformations, as St. Paul calls us to in I Corinthians 12. Such a space allows for the 'growing end' of human dignity that challenges the Church, and all within it, to recognize the ability of individuals with IDD to learn and develop and to support this, even if it means adjusting priorities for treasured programs and projects.

⁵⁷⁹ Karl Rahner, *The Love of Jesus and the Love of Neighbor* (Crossroad Publishing Company, 1983), pp. 71-77.

⁵⁸⁰ Doak, "Sex, Race, and Culture: Constructing Theological Anthropology for the Twenty-First Century," pp. 508-523.

⁵⁸¹ *Ibid.*, p. 509.

D. Moving Beyond the Shadow Narrative with SRV

This chapter provides the operational framework to initiate change and to overcome the devaluation and marginalization of individuals with IDD in the US Catholic Church. Specifically, it emphasizes the importance of fostering interpersonal connections with others in their parish to promote meaningful participation in the Church. The framework builds on the strategies of *SRV* discussed in the previous chapter to understand how particular groups of peoples become marginalized.

1. The Object of SRV: Counteracting the Process of Devaluation and Marginalization

A brief summary of its purpose and principles will be helpful before moving further. *SRV* is built on two premises. It notes the importance of social roles for identity development and participation within community life and posits that some individuals are at risk of being devalued and marginalized in society as the result of typically unconscious mindsets rooted in what I have named the *shadow narrative*, within the context of this project. This marginalization limits their access to what it refers to as the good things in life, such as a home, friends, intimate relationships, participation in community and family life, a transcendent belief system, belonging to different groups, to have good health, education and the opportunity to develop one's abilities, follow one's interests, participate in decisions about one's life, participate in ordinary human social life, access to ordinary spaces of community life, to contribute to one's community and to be appreciated.⁵⁸² These are things that all people want and is similar to what Catholic Social Teaching refers to as the things necessary to live a fully human life. However, they are more difficult to obtain for individuals who are devalued in society, as was discussed in the last chapters three and six.

Achieving the above requires counteracting the process of devaluation and marginalization of the individual person, which is the object of *SRV*. For the purpose of

⁵⁸² Wolfensberger, Thomas, and Caruso, "Some of the Universal "Good Things of Life" Which the Implementation of Social Role Valorization Can Be Expected to Make More Accessible to Devalued People," pp. 12-14.

this discussion, the goal is to increase their possibilities for meaningful interaction and participation in the life of the Church, in their congregation, be valued as integral members of the Church, and that they develop a sense of belonging within it. This is achieved by facilitating positive interactions within the community, identifying valued roles within the congregation the person is interested in and developing skills to perform the roles.

Begin with the person and involve them in the process as much as possible, in age appropriate ways. Get to know them, what they are good at and are interested in, rather than what they cannot do and foster interpersonal connections within the community based on these to provide opportunities to develop relationships and natural supports in the parish. Considerations for choices should include not only shared interests, but also positive development, again with respect for the person's interests. Attend to what is 'typical and ordinary' for others of a similar age. Ignoring this reinforces the mindsets of the *shadow narrative* and will undermine plans. This is a developmental process, recognizing that ability is nurtured and continues to develop as long as it is fostered appropriately and respectfully.

Principles of SRV emphasize making informed choices based on expected outcomes regarding someone's goals. Plan for success, because bad impressions are hard to erase (*conservatism corollary*). Attend to typical opportunities, choices and ways of doing things for someone of the same age, gender and other relevant considerations (*typical and usual*). This does not mean taking things away from someone if they are important to them, but focuses on offering choices and discussing the implications of choices, as discussed about Bill's shirt preferences. This not only respects the person, but also can help foster decision-making capability.

Natural and smaller environments are more effective ways to foster participation and a sense of belonging (*individual or small*). Therefore, avoid the tendency to be 'efficient' and bring individuals with disabilities from surrounding areas together. This upsets the natural dynamics of a community and minimizes the chances to foster natural relationships and participation. Verify the plan is designed to serve the intended

person in age appropriate and respectful ways (*pastoral* coherency) and plan reviews to assess outcomes and periodically ready to make alterations as necessary.

2. Making a Decision

The first half of my thesis title asks the question of persons with IDD to the Church, "Who do you say I am?" The Church says, "You are a beloved sister or brother in Christ. You are part of the body of Christ." Wolfensberger's simple logic formula to test a plan discussed above is helpful. It also calls for a decision to validate one's commitment to a plan. In light of the persistent and contradictory marginalization of persons with intellectual and/or developmental disabilities in the life of the US Catholic Church, Wolfensberger would ask, "How earnest is this reply?" A decision is called for by the US Catholic Church. Does it mean what it says regarding persons with disabilities and within the life of the Church? Is it committed to its purported identity as God's dwelling place with humanity,⁵⁸³ the body of Christ (1 Cor 12)? Is it willing to take seriously the consequent incarnate implications of this and support real change?

If the answer is no, if the Church decides that it is too much work to live its self-proclaimed vision,

[to live in] a spirit of mutual love ... [to] build a community of interdependent people and discover the Kingdom of God in [its] midst. ...[where] people with disabilities are to become equal partners in the Christian community, injustices ... eliminated, and ignorance and apathy replaced by increased sensitivity and warm acceptance. ...⁵⁸⁴

then SRV says the vision should be abandoned. Protestations of equality and love are merely nice words, unless they are supported by thoughtful action. Otherwise, individuals with disabilities and their families will continue to be disappointed without the real commitment to understand the magnitude of the task or the dedication of the

⁵⁸³ Pontifical Council for Justice and Peace, "Compendium of Social Doctrine," par. 60.

⁵⁸⁴ USCCB, "US Pastoral Statement," par. 2, 13.

necessary resources. Without commitment, success will be limited, and outcomes will be demoralizing, deepening wounds of internalized devaluation.

However, if the answer is yes, then *SRV* can provide the lamp to overwhelm the *shadow narrative* with the light of the Gospel according to what has been presented. While *SRV* focuses attention on individuals, rather than society or large organizations, my proposal is concerned with both, which I will address more fully in the next chapter. Below are seven points of my proposal to the problem, to overcome the marginalization of individuals with IDD in the US Catholic Church.

1. It is essential for ecclesial decision to provide official and structural support that ties this to its mission. This could be at parish, (arch)diocesan, or national level.⁵⁸⁵
2. Plan for community involvement from the beginning, identifying formal and informal leaders.
3. Build a culture that is concerned with human dignity and fosters identification with persons with IDD, by acknowledging that we are all created in the image of God and share a common humanity. This will be enhanced through fostering interpersonal identification.⁵⁸⁶
4. Emphasize that compassion, as described within motivation theory of empathy, is an important social norm within this culture, which is part of concern for the common good, solidarity and subsidiarity.⁵⁸⁷
5. Educate the community about the wounding impact of the *shadow narrative* and include examples that have occurred in the Church.⁵⁸⁸
6. Focus on individual persons, with a face and name, rather than some

⁵⁸⁵ James D Kirkpatrick and Wendy Kayser Kirkpatrick, *Kirkpatrick's Four Levels of Training Evaluation*, (Alexandria, VA: ATD Press, 2016). pp. 23-48. I am grateful to Robert Flynn for this reference.

⁵⁸⁶ Zaki, "Empathy," p. 1612.

⁵⁸⁷ *Ibid.*

⁵⁸⁸ *Ibid.*, p. 1631.

faceless mass.⁵⁸⁹

7. Utilize principles of *SRV* to provide access for individuals with disabilities to participate in new, desired roles within the community and support their development of the necessary skills.

This is the outline of my proposal, based on what has been learned during this journey, to answer the question posed at the outset and the details of my constructive response. Considering Wolfensberger's influence on the development of the *US Pastoral Statement*, the US Church's position statement on theology, disability and pastoral practice, it seems to have come full circle. Understanding born out of love brings hope.

⁵⁸⁹ Ibid., pp. 1628-1634.

VIII. Becoming a Church Rooted in Human Dignity

“Friendship – my definition – is built on two things,” he said. “Respect and trust. Both elements have to be there. And it has to be mutual. You can have respect for someone, but if you don’t have trust, the friendship will crumble.”

~ Blomkvist to Salander, *The Girl With The Dragon Tattoo*

The question of the critical part of my thesis was, “Why do individuals with intellectual and developmental disabilities (IDD) continue to struggle to participate in the life of the US Catholic Church in an 'ordinary way,' despite its contradiction to principles of Catholic Social Teaching that demands respect for human dignity and it's consequential possibility to flourish to one's capacity and live a fully human life?” In the analytical chapters on development of the ministry and *US Pastoral Statement*, the *shadow narrative*, and charity, a counter narrative hidden in shadow was identified and traced within the ministry and its own development. From this I learned the answer to my research question is this, that individuals with IDD continue to be devalued and marginalized within the Church because of this *shadow narrative*. Its five threads are a subset of other threads which have devalued and marginalized groups of people throughout time. The decision about who is devalued is determined within the powerbase of the normative culture. The main concern for the constructive part of my thesis asks if there is a way to overcome this rupture between what the Church professes about individuals with IDD and their lived experiences within pastoral practices in the Church. I found SRV provides the promise to explain and a method to counteract this marginalization compatibly within the theological framework of the body of Christ. It is based on the principles of Catholic Social Teaching, which holds together the tensions between individual and community concerns, to address a persistent problem, re-educate the Church at large and reform it within its self-proclaimed identity.

Marginalization is not a new phenomenon in human society. It happened in Paul's day in the Church in Corinth, drawing his chastisement for undermining the embodiment of the Spirit within the community. This diminishment motivated Paul to apply a familiar metaphor of society as a human body to the Church, which is not just

any body, but the body of Christ. So, while a human body is concerned about an individual's health and sustenance, the body of Christ is concerned about something much more. The body of Christ must edify Christ, making him present in the world. Diversity is required to be holistically functional and not a monstrosity (Cor 12:15-20), as well as compassionate respect and acceptance of its interdependent nature and concern for the common good.

A number of different experiences of individuals with IDD within the Church have been explored in these many pages. They have been evaluated in consideration of the vision proclaimed by the US Catholic Bishops in their *US Pastoral Statement on Persons with Disabilities*. Some of the stories illustrate the possibilities of who and what the Church proclaims to be, and others do not. Traveling through the development of ministry with persons with IDD in the US Church, I discovered the *shadow narrative* woven throughout, even in some of the words of the *US Pastoral Statement*, a document which is still a prophetic voice despite this intrusion. It undermines basic premises of Catholic Social Teaching and diminishes rather than respects the innate dignity of individuals with disabilities as human persons, created in God's image. The contrary images of individuals with disabilities chronicled in the *shadow narrative* are ascribed by others, therefore restricting them within dependent, conscripted spaces, rather than allowing for development and new possibilities. The outcome of the *shadow narrative* devalues and marginalizes individuals with disabilities in the US Catholic Church.

Revitalizing the traditional understanding of the body of Christ based on this offers new potential for the Church to be faithful to its mission. *Social Role Valorization* provides the framework, and relationships are the critical conduit for delivery, within the body of Christ, working for change one person at a time. It provides the tools for all people to engage with each other in the spaces *between* people, where the Spirit works and can become manifest.

The vision from the Church in the *Pastoral Statement of the US Bishops on Persons with Disabilities* is clear. It makes a promise, gives a call to action and issues a challenge to the Church and all people of good will. Within these it shares a vision of the

Church that emphasizes the importance of shared human dignity and responsibility for each other, inclusive of individuals with disabilities; it acknowledges that prejudices against persons with disabilities have resulted in the unjust marginalization of them and calls the Church to respond with justice and compassion to correct this, not only for the benefit of individuals with disabilities, but because “the Church finds its true identity when it fully integrates itself” with people with disabilities and others who have been marginalized as well.⁵⁹⁰ This moves far beyond individuals with disabilities confined within restricted spaces based on their disability to relationships of reciprocity and sounds quite a bit like making way for more possibilities for manifestations of the Spirit. Realizing this will not be an easy transformation, the bishops say, and it will require education of all within the Church.⁵⁹¹ Wolfensberger’s influence is clearly discernable in both points noted.

The task ahead is to nurture an interdependent culture within the Church that is animated by love, which is evidenced in the many different episodes of call and response reflecting the active presence of the Spirit, which is continually renewing and evolving, as in Reynold’s provocative metaphor of jazz, generated through the many calls and responses between musicians in a jazz band.⁵⁹²

This is a powerful image that anticipates real synergy at the intersection of theology, disability and pastoral practice in the US Catholic Church! Such would hopefully allow the approximately 87% of individuals with severe disabilities whose faith is important to them to participate within the life and mission of the Church at least to levels consistent with individuals without disabilities.⁵⁹³ Parents would no longer leave or

⁵⁹⁰ USCCB, “US Pastoral Statement,” par 12.

⁵⁹¹ Ibid., par 20.

⁵⁹² Reynolds, “Improvising Together: Christian Solidarity and Hospitality as Jazz Performance,” pp. 39-43, 47-50; Cahalan and Miller-McLemore, *Calling All Years Good: Christian Vocation Throughout Life's Seasons*, pp. 12-31.

⁵⁹³ Harris Interactive, “2004 National Organization on Disability/Harris Survey of Americans with Disabilities.”; “The ADA, 20 Years Later.”

consider changing their parish because of how their sons and daughters with disabilities were treated.⁵⁹⁴ If the Church were to model for the rest of society respect for the dignity of individuals with disabilities and appreciate them as indispensable members of the body of Christ, it could have significant impact on their lives. Individuals with IDD meaningfully participating in the life of the Church in genuinely valued ways, developing relationships and feeling a true sense of belonging would turn the space *OTM* into an empty lot. Valued and no longer marginalized, individuals with IDD should no longer be three times more likely to live below poverty level, four times as likely to suffer physical violence and bullying leveled against them or prenatally at risk of not being born 80 percent of the time.⁵⁹⁵ Such a place could surely be filled with manifestations of the Spirit!

A. Details of a Plan

How to set this in motion and start down the path? I have identified seven steps to accomplish this, agreeing with the US bishops that this will not be an easy road and that education is critical and should initiate the process. These steps are drawn from the framework and strategies of *SRV* and reinforced by implications of research into motivation theory of empathy its applications.⁵⁹⁶ However, the motivation and guiding principles are based on the essentials of Catholic Social Teaching, calling for respect for human dignity and promoted within its principles of concern for the common good,

⁵⁹⁴ Ault, Collins, and Carter, "Congregational Participation and Supports for Children and Adults with Disabilities: Parent Perceptions," p. 55. 32%. ; O'Hanlon, "Religion and Disability: The Experiences of Families of Children with Special Needs," p. 52. 38%.

⁵⁹⁵ Petersilia, "Crime Victims with Developmental Disabilities: A Review Essay."; Blake et al., "National Prevalence Rates of Bully Victimization among Students with Disabilities in the United States."; D Almeida et al., "Perinatal Hospice: Family-Centered Care of the Fetus with a Lethal Condition."

⁵⁹⁶ Zaki, "Empathy," pp. 1608-1611; For more about interesting possibilities of increasing empathic ability, this book is very interesting. *The War for Kindness: Building Empathy in a Fractured World*. pp. 10-12, 17-50, 74-92, 144-167.

solidarity and subsidiarity. While *SRV* focuses attention on individuals, rather than society or large organizations, my proposal is concerned with both, which I will speak more about shortly. The seven points are:

1. It is essential for ecclesial decision to provide official and structural support that ties this to its mission. This could be at parish, (arch)diocesan, or national level.⁵⁹⁷
2. Plan for community involvement from the beginning, identifying formal and informal leaders.
3. Build a culture that is concerned with human dignity and fosters identification with persons with IDD, by acknowledging that we are all created in the image of God and share a common humanity. This will be enhanced through fostering interpersonal identification.⁵⁹⁸
4. Emphasize that compassion, as described within motivation theory of empathy, is an important social norm within this culture, which is part of concern for the common good, solidarity and subsidiarity.⁵⁹⁹
5. Educate the community about the wounding impact of the *shadow narrative* and include examples that have occurred in the Church.⁶⁰⁰
6. Focus on individual persons, with a face and name, rather than some faceless mass.⁶⁰¹
7. Utilize principles of *SRV* to provide access for individuals with disabilities to participate in new, desired roles within the community and support their development of the necessary skills.

⁵⁹⁷ Kirkpatrick and Kirkpatrick, *Kirkpatrick's Four Levels of Training Evaluation*. pp. 23-48. I am grateful to Robert Flynn for this reference.

⁵⁹⁸ Zaki, "Empathy," p. 1612.

⁵⁹⁹ Ibid.

⁶⁰⁰ Ibid., p. 1631.

⁶⁰¹ Ibid., pp. 1628-1634.

1. Ecclesial Support

The first point recognizes that that real change cannot happen without official buy in and intentional structural support. However, this does not mean starting a new program. It means for the Church to intentionally plan to live out what it proclaims about itself, I know that this will not happen overnight. While I have strong ideas about the general approach, my ideas for full implementation are still developing. However, there are some points that are important. The process should be positioned as part of an overall concern for accountability to the mission of the Church.⁶⁰² This reeducation that the US Bishops referred to, which should really be considered re-forming or re-formation, needs to include unpacking the implications of living as the body of Christ, and identifying ruptures between mission, stated values and the actions of the community. This can make the difference between realizing anywhere from 5 to 80 percent or more effectiveness.⁶⁰³ These considerations should inform all pastoral development plans to increase meaningful participation within congregational life for persons with IDD, as well as for any other marginalized group, or person for that matter.

I note three possible levels of focus: parish, (arch)diocese, or national. While there certainly could be coordination with universal Church, the feedback loop will be much slower and most likely has more considerations, such as culture and interconnectedness. If the US Church is sincerely interested, I would recommend reconsidering the decision about identifying ministry with persons with disabilities as a focus ministry of the USCCB, as Bishop Lyons suggested during the development of the

⁶⁰² For more on designing effective training to change behavior, a useful resource is Kirkpatrick and Kirkpatrick, *Kirkpatrick's Four Levels of Training Evaluation*. pp. 23-48. I am grateful to Robert Flynn for this reference and his strong recommendation to note it and consider for future development.

⁶⁰³ Robert O Brinkerhoff, "Increasing Impact of Training Investments: An Evaluation Strategy for Building Organizational Learning Capability," *Industrial and Commercial Training* (2006): p. 302.

US Pastoral Statement.⁶⁰⁴ Lyons had recommended it be treated with the same level of importance as other officially highlighted ministries, such as evangelization and respect life. It is not hard to imagine that this would result in increased consistency and effectiveness, if this was done. Any initiatives of the USCCB would then include relevant concerns for individuals with disabilities as part of the planning and assessment process. *NDPD* could still be an outside organization if it thinks that is best.

2. *Involve the Community*

Inviting/encouraging full community participation is critical. This will not be an easy transition for many people. The formation process will need to be considered very carefully. Be prepared for resistance from some. The *shadow narrative* presents very particular mindsets from society which reinforce the 'cult of normalcy'. Although the first four threads are positively motivated, on the surface at least, they do reinforce positions of power and esteem that strongly influence life within the Church and society. In fact, the principles of *SRV* should be considered as part of the community development process as well.

The process needs to be intentional, yet expressed such that people can hear it. In other words, work with the community, collaborate and involve all in the process as well.⁶⁰⁵ It is important to remember that everyone can learn and develop abilities with appropriate support and expectations, based on their abilities and capacities. The same can be said for communities and the people that typically 'own' the normative spaces. The Church, individual congregations and individual members can all learn new ways of being Church if approached and supported appropriately.

⁶⁰⁴ NCCB, "Proposed Action Item Amendment: Pastoral Statement on Handicapped People." , Bishop Lyons.

⁶⁰⁵ Wolfensberger, "Social Role Valorization: A Proposed New Term for the Principle of Normalization," p. 439.

3. Culture Respecting Dignity

As human dignity is the basis of all Catholic Social Teaching, it is critical it is fully understood. The implications of it are not fully appreciated still, nor the implications of this ignorance. Attending to human dignity provides the wellspring from which to draw the interconnectedness of the human family, inclusive of individuals with disabilities, as sisters and brothers in Christ. Unpacking what it means to live as the body of Christ, as discussed in chapter five will provide such a foundation, because it challenges the predominant individualistic assumptions about the body of Christ and calls for establishing interpersonal connections, that can lead to relationships and enhance participation and sense of belonging. The process of culture building must be as intentional as step two, involving the entire community.

4. Empathy – Compassion a Critical Social Norm

Motivational empathy, compassion, is a skill that can be developed and will foster interpersonal identification, which can support increasing capacity for the three concerns of Catholic Social Teaching, concern for the common good, solidarity, and subsidiarity. Numerous studies have demonstrated the power of such identification to increase empathy toward previously marginalized groups of people, as well as to change isolating or harmful behaviors against them.⁶⁰⁶ Recalling from my earlier discussion on marginalization in chapter two, compassion or motivational empathy, moves people to action to increase someone's well-being is what is meant.

5. Shadow Narrative and Wounds

Educating the community about the wounding impact of the *shadow narrative* will begin by first introducing the *shadow narrative* and its different threads: holy

⁶⁰⁶ Zaki, "Empathy," pp. 1611-1634; Promising indications on improving attitudes of health care providers toward individuals with disabilities by using curriculum based on informed empathy and life experiences of individuals with disabilities, see Sonya R Miller, "A Curriculum Focused on Informed Empathy Improves Attitudes toward Persons with Disabilities," *Perspectives on Medical Education* 2, no. 3 (2013): pp.114-125; McLaughlin, Byers, and Vaughn, "Responding to Bullying."

innocent/perpetual child, object of pity and opportunity for charity, special connection with Jesus and the cross, idealization or 'as best as you can,' and totally 'other.' Helping people become aware of their own unconscious mind sets will help lay the groundwork for this. I expect this to be challenging for some, because of unconscious investments they may have. Utilizing what has been learned about the process of marginalization discussed in chapter three, what Reynolds calls the *cult of normalcy*, will also be part of this. This is a very important part of the process that will take time. The Church should also consider these implications throughout its social doctrine.

6. Individual, Small, 'Natural or Typical'

The process will be easier and particularly powerful if community members with disabilities share such experiences, or allow their stories to be shared, though it must be totally voluntary. When sharing information about particular individuals, it is important to collaborate with them and their families about what information is shared.

When educating people about individuals with different kinds of disabilities, it is important to refer to real people, rather than abstract diagnostic categories, even if not part of the local community. Again, if there are individuals within a particular community, that makes it more relatable. Recall my own story about when my heart became connected with this work. It was after getting to know Ben and Justin, who totally defied the stereotypes about individuals with autism, though they both do have significant traits associated with autism.

The preference to focus on individuals is important for two types of concerns. The first is to break down barriers of discomfort about interacting with someone with a disability, someone who may communicate or move around in the world differently than one's self. The second is when trying to gather resources, financially or otherwise, to help someone. People are much quicker to share with someone they can see has needs, and also see the benefit of their generosity. Both points indicate or reflect value of natural or smaller organizations to increase interpersonal connections. Similarly, the discussion in chapter four indicates that developments within the charity tradition that focused on expanding its centralization could be at least partly culpable for its present issues.

7. Utilizing SRV to Increase Access to Meaningful Roles

This point of my plan focuses on using the strategies of SRV to promote interpersonal connections and interaction between individuals with IDD and others in the Church that includes opportunities to participate meaningfully within the body of Christ. This is not about establishing a program, it is about helping people of diverse interests, abilities and ways of moving in the world to feel comfortable together and appreciate each other's potential for growth, participation and contribution. Nothing is forced, but whatever unfolds should unfold from genuine interest in each other, from being open to the possible manifestations of the Spirit in the spaces in between all in the body.

8. Some Cautions

I expect issues related to subsidiarity to be the most challenging, because it most threatens the threads of the *shadow narrative* particularly associated with the desire to do things *for* individuals with IDD, either out of pity or because of limited expectations. It is perhaps possible to convince oneself of being concerned for the common good and to feel a sense of solidarity, even if it is based on patronizing goals. However, subsidiarity is about individuals having honest opportunities to initiate action and express their own ideas, even if done with interdependent support.

While SRV focuses on supporting individual growth, making this real within the Church will require official support for structural changes as noted above. The principles of SRV are consistent with Catholic Social Teaching and it provides an operational guide for the Church to respect the human dignity of people so it can more authentically live as the body of Christ, leaving itself open to new possibilities of mirroring and modeling God's love in the word and to support the flourishing of all people, regardless of ability or disability.

B. Future Considerations

Lex orandi, lex credendi, lex agenda, the Church's past, present actions and future held in tension together. Catholic Tradition continues to develop to be true to its

purpose. In bringing the *shadow narrative* into the light, what was hidden is now visible, specifically relative to individuals with disabilities in the US Catholic Church.

To work toward recovering the *doing* of charity in truth is to recover mutuality, in ‘the two faces of Christ,’ rather than hiding behind programmatic structures.⁶⁰⁷ As Karl Rahner says, “we cannot do anything else than see our own fate in that of our neighbor.”⁶⁰⁸ Living as the body of Christ is the realization that all are called to “journey in community side by side with others” in the details of daily life.⁶⁰⁹ Of course this is difficult. The ability to do this comes from God’s grace to transform indifferent and fearful hearts into hearts that are willing to become entangled in others’ lives.⁶¹⁰

A fuller examination of the imaging of individuals with disabilities within the Church’s theological sources and ecclesial documents is warranted if a new cohesive narrative is to be possible. Questions raised here about theological anthropology is related to this. I only made a small contribution here to the larger subject to begin the conversation, but much more is needed, including how disability is addressed in seminary formation. Rather than only being included in pre-theology courses or some elective module, disability should be woven throughout the curriculum: theological anthropology, ecclesiology, liturgy, etc.

Catholic charitable organizations may benefit from considering implications for their work based on the issues covered in chapter four that may have influenced the current perception problems of charity. Are there remnants in their activities from the questionable turns noted during development of the practice of charity? Relatedly, I would appreciate feedback from historians familiar with this area, if they agree with my interpretations.

⁶⁰⁷ Pope Benedict XVI, *Caritas in Veritate (Charity in Truth)*. par. 7.

⁶⁰⁸ Karl Rahner, “Christology Today?,” *Theological investigations* 14 (1966): p. 32.

⁶⁰⁹ Pope Francis, “Gaudete Et Exsultate (Rejoice and Be Glad),” par 141.

⁶¹⁰ *Ibid.*, par 139-146.

IX. Appendix

*A. Pastoral Statement of U.S. Catholic Bishops on People with Disabilities*⁶¹¹

1. The same Jesus who heard the cry for recognition from the people with disabilities of Judea and Samaria 2,000 years ago calls us, His followers, to embrace our responsibility to our own disabled brothers and sisters in the United States. The Catholic Church pursues its mission by furthering the spiritual, intellectual, moral and physical development of the people it serves. As pastors of the Church in America, we are committed to working for a deeper understanding of both the pain and the potential of our neighbors who are blind, deaf, mentally retarded, emotionally impaired, who have special learning problems, or who suffer from single or multiple physical handicaps—all those whom disability may set apart. We call upon people of good will to reexamine their attitudes toward their brothers and sisters with disabilities and promote their well-being, acting with the sense of justice and the compassion that the Lord so clearly desires. Further, realizing the unique gifts individuals with disabilities have to offer the Church, we wish to address the need for their integration into the Christian community and their fuller participation in its life.

2. Prejudice starts with the simple perception of difference, whether that difference is physical or psychological. Down through the ages, people have tended to interpret these differences in crude moral terms. *Our* group is not just different from *theirs*; it is better in some vague but compelling way. Few of us would admit to being prejudiced against people with disabilities. We bear them no ill will and do not knowingly seek to abrogate their rights. Yet people with disabilities are visibly, sometimes bluntly different from the *norm*, and we react to this difference. Even if we do not look down upon them, we tend all too often to think of them as somehow apart -- not completely *one of us*.

3. What individuals with disabilities need, first of all, is acceptance in this difference that can neither be denied nor overlooked. No acts of charity or justice can be of lasting value unless our actions are informed by a sincere and understanding love that penetrates the wall of strangeness and affirms the common humanity underlying all distinction. Scripture teaches us that "any other commandment there may be [is] all summed up in this: 'You shall love your neighbor as yourself.'" (Rom.13:9) In His wisdom, Jesus said, "as yourself." We must love others from the inside out, so to speak, accepting their difference from us in the same way that we accept our difference from them.

⁶¹¹ (Copyrighted by USCCB.) November 16, 1978 (reprinted with updated language), 1989.

The Church's Response to the Person with a Disability

4. Concern for people with disabilities was one of the prominent notes of Jesus' earthly ministry. When asked by John's disciples, "Are you He who is to come or do we look for another?" Jesus responded with words recalling the prophecies of Isaiah "Go back and report to John what you hear and see; the blind recover their sight, the lame walk, the lepers are cleansed, the deaf hear, dead men are raised to life, and the poor have the Gospel preached to them." (Mt. 11:3-5) Persons with disabilities become witnesses for Christ, His healing of their bodies a sign of the spiritual healing He brought to all people. "Which is less trouble to say, 'Your sins are forgiven' or 'Stand up and walk?' To help you realize that the Son has authority on earth to forgive sins" -- He then said to the paralyzed man -- "Stand up! Roll up your mat and go home" (Mt. 9:5f).

5. The Church that Jesus founded would surely have been derelict had it failed to respond to His example in its attention to people with disabilities. It remains faithful to its mission when its members become more and more a people of the Beatitudes, a people blessed in their meekness, their suffering, their thirst for righteousness. We all struggle with life. We must carry on this struggle in a spirit of mutual love, inspired by Christ's teaching that in serving others we serve the Lord Himself. (cf. Mt. 25:40) In doing so, we build a community of interdependent people and discover the Kingdom of God in our midst.

6. The Church, through the response of its members to the needs of their neighbors and through its parishes, healthcare institutions and social service agencies, has always attempted to show a pastoral concern for individuals with disabilities. However, in a spirit of humble candor, we must acknowledge that at times we have responded to the needs of some of our people with disabilities only after circumstances or public opinion have compelled us to do so. By every means possible, therefore, the Church must continue to expand its healing ministry to these persons, helping them when necessary, working with them and raising its voice with them and with all members of society who are their advocates. Jesus revealed by His actions that service to and with people in need is a privilege and an opportunity as well as a duty. When we extend our healing hands to others, we are healed ourselves.

7. On the most basic level, the Church responds to persons with disabilities by defending their rights. Pope John XXIII's encyclical *Pacem in Terris* stresses the innate dignity of all men and women. "In an ordered and productive community, it is a fundamental principle that every human being is a 'person'. . . . [One] has rights and duties . . . flowing directly and spontaneously from [one's] very nature. These rights are therefore universal, inviolable and inalienable." (9)

8. The word *inalienable* reminds us that the principles on which our democracy is founded also guarantee certain rights to all Americans, regardless of their circumstances. The first of these, of course, is the right to life. We have spoken out on

this issue on many occasions. We see defense of the right to life of persons with disabilities as a matter of particular urgency, however, because the presence of handicapping conditions is not infrequently used as a rationale for abortion. Moreover, those babies with severe disabilities who are permitted to be born are sometimes denied ordinary and usual medical procedures.

9. All too often, abortion and postnatal neglect are promoted by arguing that the infant will survive only to suffer a life of pain and deprivation. We find this reasoning appalling. Society's frequent indifference to the plight of citizens with disabilities is a problem that cries aloud for solutions based on justice and conscience, not violence. All people have a clear duty to do what lies in their power to improve living conditions for people with disabilities, rather than ignoring them or attempting to eliminate them as a burden not worth dealing with.

10. Defense of the right to life, then, implies the defense of other rights which enable the individual with a disability to achieve the fullest measure of personal development of which he or she is capable. These include the right to equal opportunity in education, in employment, in housing, as well as the right to free access to public accommodations, facilities and services. Those who must be institutionalized deserve decent, personalized care and human support as well as the pastoral services of the Christian community. Institutionalization will gradually become less necessary for some as the Christian community increases its awareness of disabled persons and builds a stronger and more integrated support system for them.

11. It is not enough merely to affirm the rights of people with disabilities. We must actively work to make them real in the fabric of modern society. Recognizing that individuals with disabilities have a claim to our respect because they are persons, because they share in the one redemption of Christ, and because they contribute to our society by their activity within it, the Church must become an advocate for and with them. It must work to increase the public's sensitivity toward the needs of people with disabilities and support their rightful demand for justice. Moreover, individuals and organizations at every level within the Church should minister to persons with disabilities by serving their personal and social needs. Many can function on their own as well as anyone in society. For others, aid would be welcome. All of us can visit persons unable to leave their homes, offer transportation to those who cannot drive, read to those who cannot read, speak out for those who have difficulty pleading their own case. In touching the lives of men, women and children in this way, we come closest to imitating Jesus' own example, which should be always before our eyes. (cf. Lk. 4:17-19, 21)

Persons with Disabilities and the Ecclesial Community

12. Just as the Church must do all in its power to help ensure people with disabilities a secure place in the human community, so it must reach out to welcome gratefully those who seek to participate in the ecclesial community. The central meaning of Jesus' ministry is bound up with the fact that He sought the company of people who, for one reason or another, were forced to live on the fringe of society. (cf. Mk. 7:37) These He made the special object of His attention, declaring that the last would be first and that the humble would be exalted in His Father's kingdom. (cf. Mt. 20: 16, 23:12) The Church finds its true identity when it fully integrates itself with these *marginal* people, including those who suffer from physical and psychological disabilities.

13. If people with disabilities are to become equal partners in the Christian community, injustices must be eliminated and ignorance and apathy replaced by increased sensitivity and warm acceptance. The leaders and the general membership of the Church must educate themselves to appreciate fully the contribution people with disabilities can make to the Church's spiritual life. They bring with them a special insight into the meaning of life; for they live, more than the rest of us perhaps, in the shadow of the cross. And out of their experience they forge virtues like courage, patience, perseverance, compassion and sensitivity that should serve as an inspiration to all Christians.

14. In the case of many people with disabilities, integration into the Christian community may require nothing more than issuing an invitation and pursuing it. For some others, however, full participation can only come about if the Church exerts itself to devise innovative programs and techniques. At the very least, we must undertake forms of evangelization that speak to the particular needs of individuals with disabilities, make those liturgical adaptations which promote their active participation and provide helps and services that reflect our loving concern.

15. This concern should be extended also to the families and especially the parents. No family is ever really prepared for the birth of a child with a disability. When such a child does come into the world, families often need strong support from their faith community. That support must remain firm with the passage of years. The path to independence can be difficult. Family members need to know that others stand with them, at least in spirit, as they help their children along this path.

16. The central importance of family members in the lives of all people with disabilities, regardless of age, must never be underestimated. They lovingly foster the spiritual, mental and physical development of the disabled person and are the primary teachers of religion and morality. Ministers working in the apostolate with persons with disabilities should treat them as a uniquely valuable resource for understanding the various needs of those they serve.

17. Full participation in the Christian community has another important aspect that must not be overlooked. When we think of people with disabilities in relation to ministry, we tend automatically to think of doing something for them. We do not reflect that they can do something for us and with us. As noted above, people with disabilities can, by their example, teach the non-disabled person much about strength and Christian acceptance. Moreover, they have the same duty as all members of the community to do the Lord's work in the world, according to their God-given talents and capacity. Because individuals may not be fully aware of the contribution they can make, Church leaders should consult with them, offering suggestions on practical ways of serving.

Parish Level

18. For most Catholics the community of believers is embodied in the local parish. The parish is the door to participation for individuals with disabilities, and it is the responsibility of the pastor and lay leaders to make sure that this door is always open. We noted above that the task, on occasion, may not be an easy one; involving some people in parish life may challenge the ingenuity and commitment of the entire congregation. Yet, in order to be loyal to its calling, to be truly pastoral, the parish must make sure that it does not exclude any Catholic who wishes to take part in its activities.

19. If the participation of persons with disabilities and their families is to be real and meaningful, the parish must prepare itself to receive them. This preparation might begin with a census aimed at identifying parishioners and those with no church affiliation who have significant disabilities. Parish leaders could then work with individuals and their families to determine what steps, if any, are needed to facilitate their participation in parish life.

20. It may be necessary at this initial stage to place considerable emphasis upon educating the members of the parish community on the rights and needs of local people with disabilities. All too often one hears that there are too few persons with disabilities in a given parish to warrant ramped entrances, special liturgies or education program. Some say these matters should be handled on the diocesan level. Although many parishes have severely limited resources, we encourage all to make the best effort their circumstances permit. No parishioner should be excluded on the basis of disability alone.

21. The most obvious obstacle to participation in parish activities faced by many people with disabilities is the physical design of parish buildings. Structurally inaccessible buildings are at once a sign and a guarantee of their isolation from the community. Sometimes all that is required to remedy the situation is the installation of outside ramps and railings, increased lighting, minor modification of toilet facilities, and perhaps, the removal of a few pews and kneelers. In other cases, major alterations and redesign of equipment may be called for. Each parish must examine its own situation to determine

the feasibility of such alterations. Mere cost must never be the exclusive consideration, however, since the provisions of free access to religious functions for all interested people is a pastoral duty.

22. Whenever parishes contemplate new construction, they should make provision in their plans for the needs of individuals with disabilities. If both new construction and the adaptation of present buildings are out of the question, the parish should devise other ways to reach its members with disabilities. In cooperation with them, parish leaders may locate substitute facilities, for example, or make a concerted effort to serve at home those who cannot come to church.

23. It is essential that all forms of the liturgy be completely accessible to people with disabilities, since these forms are the essence of the spiritual tie that binds the Christian community together. To exclude members of the parish from these celebrations of the life of the Church, even by passive omission, is to deny the reality of that community. Accessibility involves far more than physical alterations to parish buildings. Realistic provision must be made for persons with disabilities to participate fully in the Eucharist and other liturgical celebrations such as the sacraments of Reconciliation, Confirmation and Anointing of the Sick. The experiences and needs of individuals with disabilities vary, as do those of any group of people. For some with significant disabilities, special liturgies may be appropriate. Other will not require such liturgies, but will benefit if certain equipment and services are made available to them. Celebrating liturgies simultaneously in sign language enables the deaf person to enter more deeply into their spirit and meaning. Participation aids such as Mass books and hymnals in large print or Braille serve the same purpose for blind or partially sighted members.

24. People can also play a more active role in the liturgy if provided with proper aids and training. Blind parishioners can serve as lectors, for example, and deaf parishioners as special ministers of the Eucharist. We look forward to the day when more individuals with disabilities are active in the full-time, professional service of the Church, and we applaud recent decisions to accept qualified candidates for ordination or the religious life in spite of their significant disabilities.

25. Evangelization and catechesis for individuals with disabilities must be geared in content and method to their particular situation. Specialized catechists should help them interpret the meaning of their lives and should give witness to Christ's presence in the local community in ways they can understand and appreciate. We hasten to add, however, that great care should be taken to avoid further isolation of people through these programs, which as far as possible, should be integrated with the normal catechetical activities of the parish. We have provided guidelines for the instruction of persons with disabilities and for their participation in the liturgical life of the church in *Sharing the Light of Faith: National Catechetical Directory for Catholics of the United States*.

26. Finally, parishes must be sensitive to the social needs of members with disabilities. We have already touched on some ways in which Christians can express their concern for their brothers and sisters with disabilities. These actions and others like them can help solve some of the individual's practical problems. They also create an opportunity for disabled and non-disabled people to join hands and break down the barriers that separate them. In such an interchange, it is often the person with a disability who gives the gift of most value.

Diocesan Level

27. Efforts to bring people with disabilities into the parish community are more likely to be effective if the parishes are supported by offices operating at the diocesan level. At present, the social service needs of individuals with disabilities and their families are usually addressed by established diocesan agencies. Where it is found to be inadequate, the program should be strengthened to assure that specialized aid is provided to people with disabilities. In those cases where there is no program at all, we urge that one be established.

28. The clergy, religious and laity engaged in this program should help the parish by developing policy and translating it into practical strategies for working with individuals with disabilities. They should serve as advocates, seeking help from other agencies. Finally, they should monitor public policy and generate multifaceted educational opportunities for those who minister to and with people with disabilities.

29. Many opportunities for action at the diocesan level now exist with regard to public policy. Three pieces of federal legislation that promise significant benefits to individuals with disabilities have been passed during the seventies; each calls for study and possible support. We refer to the Rehabilitation Amendments of 1974, and the Education for All Handicapped Children Act of 1975. Enforcement of the regulations implementing Section 504 of the Rehabilitation Act, which forbids discrimination on the basis of disabling conditions, is a matter of particular interest. In response to the Rehabilitation Amendments, the executive branch of the federal government has also taken recent action, sponsoring a White House Conference on Handicapped Individuals in 1977. This conference was attended by official state delegations, and there would be value in determining which of its recommendations are being applied in the state or states where a given diocese is located. Diocesan offices will also wish to keep abreast of general public policy and practice in their states.

30. Dioceses might make their most valuable contribution in the area of education. They should encourage and support training for all clergy, religious, seminarians and lay ministers, focusing special attention on those actually serving individuals with disabilities, whether in parishes or some other setting. Religious education personnel

could profit from guidance in adapting their curricula to the needs of learners with disabilities, and Catholic elementary and secondary school teachers could be provided in-service training in how best to integrate students with disabilities into programs of regular education. The diocesan office might also offer institutes for diocesan administrators who direct programs with an impact on persons with disabilities.

31. The coordination of educational services within the dioceses should supplement the provision of direct educational aids. It is important to establish liaisons between facilities for people with disabilities operating under Catholic auspices (special, residential and day schools; psychological services and the like) and usual Catholic school programs. Only in this way can the structural basis be laid for the integration, where feasible, of students with disabilities into programs for non-disabled persons. Moreover, in order to ensure the widest possible range of educational opportunities, Catholic facilities should be encouraged to develop working relationships both among themselves and with private and public agencies serving the same population.

National Level

32. As the most visible expression of our commitment, we the bishops now designate ministry to people with disabilities as a special focus for the National Conference of Catholic Bishops and the U.S. Catholic Conference. This represents a mandate to each office and secretariat, as it develops its plans and programs, to address the concerns of individuals with disabilities. Appropriate offices should also serve as resource and referral centers to both parochial and diocesan bodies in matters relating to the needs of our brothers and sisters with disabilities.

Concluding Remarks

33. People with disabilities are not looking for pity. They seek to serve the community and to enjoy their full baptismal rights as members of the Church. Our interaction with them can and should be an affirmation of our faith. There can be no separate Church for people with disabilities. We are one flock that serves a single shepherd.

34. Our wholeness as individuals and as the people of God lies in openness, service and love. The bishops of the United States feel a concern for individuals with disabilities that goes beyond their spiritual welfare to encompass their total well-being. This concern should find expression at all levels. Parishes should maintain their own programs of ministry with people with disabilities, and dioceses should make every effort to establish offices that coordinate this ministry and support parish efforts. Finally, the National Conference of Catholic Bishops and the U.S. Catholic Conference will be more vigilant in promoting ministry with persons with disabilities throughout the structure of the Church.

35. We look to the future with what we feel is a realistic optimism. The Church has a tradition of ministry to people with disabilities, and this tradition will fuel the stronger, more broadly based efforts called for by contemporary circumstances. We also have faith that our quest for justice, increasingly enlisted on the side of individuals with disabilities, will work powerfully in their behalf. No one would deny that every man, woman and child has the right to develop his or her potential to the fullest. With God's help and our own determination, the day will come when that right is realized in the lives of all people with disabilities.

AN INDEX TOPASTORAL STATEMENT OF U.S.CATHOLIC BISHOPS ON PEOPLE WITH DISABILITIES edited by Father George Kuryvial, O.M.I.

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Original Title: *Pastoral Statement of U.S. Catholic Bishops on Handicapped People* Copyright, United States Catholic Conference, 1978 (reprinted with updated language), 1989.

*B. House Churches and the Eucharist Diagrams from
Jerome Murphy O'Connor⁶¹²*

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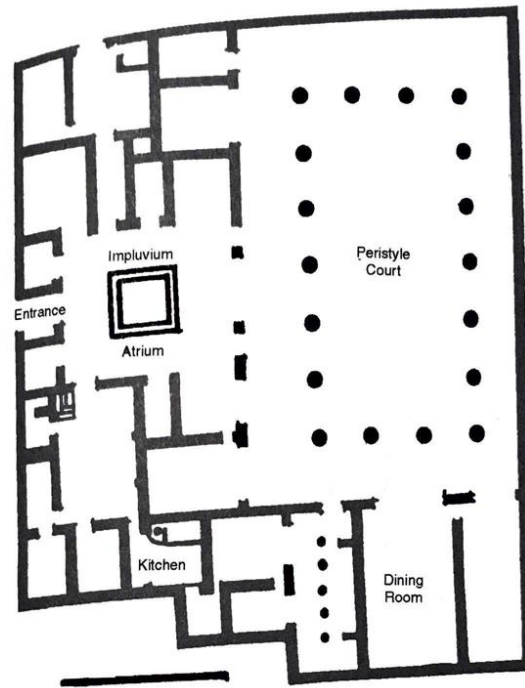


Figure 8. The House of the Vettii at Pompeii

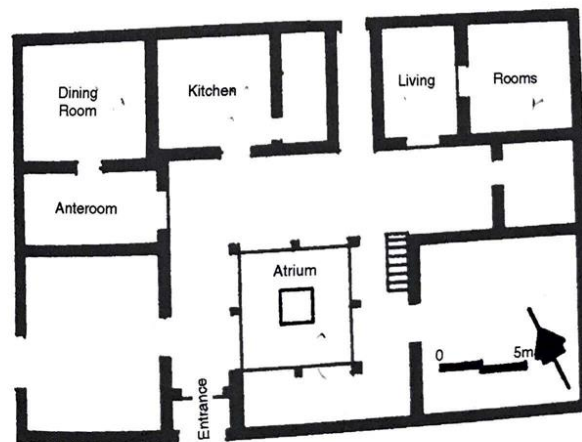


Figure 9. The Villa of Good Fortune at Olympia

⁶¹² Murphy-O'Connor, *St. Paul's Corinth: Texts and Archaeology*, pp. 181, 171.

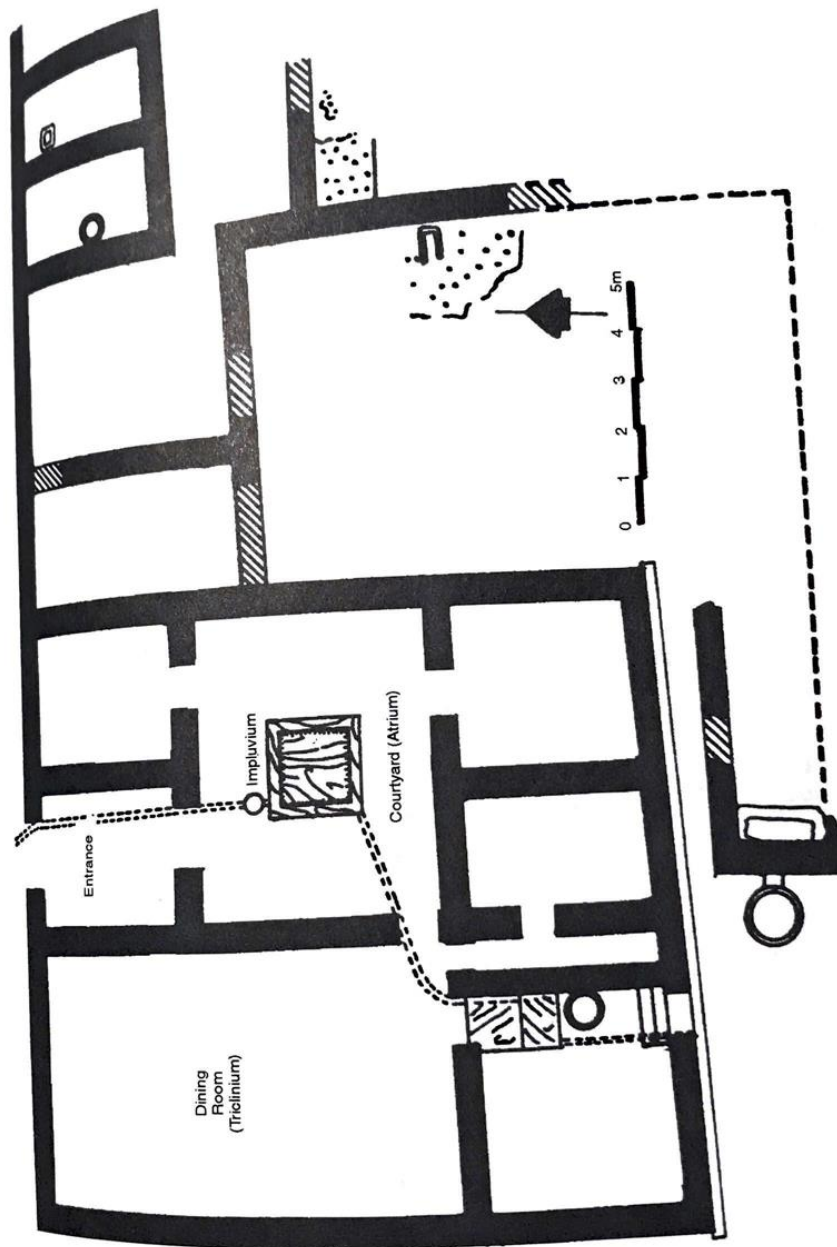


Figure 7. The Roman Villa at Anaploga

X. Literature

- AAIDD. "Frequently Asked Questions on Intellectual Disability." American Association on Intellectual and Developmental Disabilities, <http://aaidd.org/intellectual-disability/definition/faqs-on-intellectual-disability>.
- Achtemeier, Paul J, and Roger S Boraas. *The Harper Collins Bible Dictionary*. HarperOne, 1996.
- Ad Hoc Committee of the General Assembly. "Convention on the Rights of Persons with Disabilities." New York: United Nations, 2006.
- Amado, Angela Novak. "Building Relationships between Adults with Intellectual Disabilities and Community Members: Strategies, Art, and Policy." *Research and Practice in Intellectual and Developmental Disabilities* 1, no. 2 (2014): 111-122.
- . "Community Building, Friendships and Social Relationships." In *Developmental Disabilities Lecture Series*. Woodbridge Hilton, Iselin NJ: Elizabeth M. Boggs Center on Developmental Disabilities, 2011.
- . "Friends. A Manual for Connecting Persons with Disabilities and Community Members." (1990).
- Anderson, H., and E. Foley. *Mighty Stories, Dangerous Rituals*. San Francisco: Jossey-Bass, 2007.
- Apostolic Delegate. "Apostolic Letter Notification of Benediction from Pope Paul Vi on Work of NAMR." *NAMR* 1, no. 1 (September 1968).
- Aquinas, Thomas. *Summa Theologica: Translated by Fathers of the English Dominican Province*. Coyote Canyon Press, 2010.
- Armstrong, John, and Lynda Shevellar. "Re-Thinking Respite." *The SRV Journal* 1, no. 1 (2006): 14-25.
- Ault, Melinda Jones, Belva C Collins, and Erik W Carter. "Congregational Participation and Supports for Children and Adults with Disabilities: Parent Perceptions." *Intellectual and developmental disabilities* 51, no. 1 (2013): 48-61.
- Bal, Mieke. *Narratology: Introduction to the Theory of Narrative*. University of Toronto Press, 2009.
- Barbour, Ian G. *Myths, Models, and Paradigms: A Comparative Study in Science and Religion*. San Francisco, New York, London: Harper & Row 1976. Online Database.

- Baum, Michelle N., and Janice L. Benton. "The Evolution and Current Focus of Ministry with Catholics with Disabilities within the United States." *Journal of Religion, Disability & Health* 10, no. 1-2 (2006/05/31 2006): 39-54.
- Becker, Amy Julia. *A Good and Perfect Gift: Faith, Expectations, and a Little Girl Named Penny*. Kindle ed.: Bethany House, 2011.
- Benedict of Nursia. "*RB 1980: The Rule of St. Benedict in English*." edited by Timothy Fry, OSB. Collegeville, MN: Liturgical Press, 1982.
- Benton, Janice LaLonde, and Mary Jane Owen, eds. *Opening Doors to People with Disabilities* 3vols. Vol. II A and II B, Opening Doors, vol. The Resource File. Washington, D.C.: NCPD, 1995.
- , eds. *Opening Doors to People with Disabilities* 3vols. Vol. II B, Opening Doors, vol. The Resource File. Washington, D.C.: NCPD, 1995.
- Blake, Jamilia J, Emily M Lund, Qiong Zhou, Oi-man Kwok, and Michael R Benz. "National Prevalence Rates of Bully Victimization among Students with Disabilities in the United States." *School Psychology Quarterly* 27, no. 4 (2012): 210.
- Board, NAMR. "Organizing the Special Religious Education Center for Mentally Retarded Children." *NAMR Quarterly Publication* 1, no. 1 (September 1968): 14-15, 20.
- Boorstein, Michele. "Catholic Bishops Call Trump's Asylum Rules 'Immoral,' with One Suggesting 'Canonical Penalties' for Those Involved." *Washington Post*, June 13 5:59 pm EDT 2018.
- Brinkerhoff, Robert O. "Increasing Impact of Training Investments: An Evaluation Strategy for Building Organizational Learning Capability." *Industrial and Commercial Training* (2006).
- Brock, Brian. "Augustine's Hierarchies of Human Wholeness and Their Healing." Chap. 2 In *Disability in the Christian Tradition: A Reader*, edited by Brian Brock and John Swinton, 65-100. Grand Rapids, MI; Cambridge, U.K.: William B. Eerdmans Publishing Company, 2012.
- . "Theologizing Inclusion: 1 Corinthians 12 and the Politics of the Body of Christ." *Journal of Religion, Disability & Health* 15, no. 4 (2011): 351-376.
- Brown, Ford Madox. "Jesus Washing Peter's Feet."
<http://www.victorianweb.org/painting/fmb/paintings/1.html>

Brown, Raymond E, Carolyn Osiek, and Pheme Perkins. "Early Church." In *The New Jerome Biblical Commentary*, edited by Raymond Edward Brown, Joseph A Fitzmyer and Roland Edmund Murphy, 1338-1353. Upper Saddle River, NJ: Prentice Hall, 1968.

Cahalan, Kathleen A, and Bonnie J Miller-McLemore. *Calling All Years Good: Christian Vocation Throughout Life's Seasons*. Wm. B. Eerdmans Publishing, 2017.

Campion, Donald R, S.J. "The Church Today." In *The Documents of Vatican II: In a New and Definitive Translation, with Commentaries and Notes by Catholic, Protestant, and Orthodox Authorities*, edited by Walter M Abbott New York: Crossroad Publishing Company, 1966.

Carter, Erik W. "From Barriers to Belonging." In *Summer Institute of Disability and Theology 2017*. Azusa, CA,, 2017.

———. "A Place of Belonging: Research at the Intersection of Faith and Disability." *Review & Expositor* 113, no. 2 (2016): 167-180.

Carter, Erik W, Elizabeth E Biggs, and Thomas L Boehm. "Being Present Versus Having a Presence: Dimensions of Belonging for Young People with Disabilities and Their Families." *Christian Education Journal* 13, no. 1 (2016): 19.

Carter, Erik W, Thomas L Boehm, Elizabeth E Biggs, Naomi H Annandale, Courtney E Taylor, Aimee K Looch, and Rosemary Y Liu. "Known for My Strengths: Positive Traits of Transition-Age Youth with Intellectual Disability and/or Autism." *Research and Practice for Persons with Severe Disabilities* 40, no. 2 (2015): 101-119.

Catholic Church. *Catechism of the Catholic Church*. Second ed. Citta del Vaticano: Libreria Editrice Vaticana, 1997. 1994.

———. "The Rites of the Catholic Church." Chap. Introduction. Collegeville, MN: Liturgical Press, 1990.

Clark, Meghan J. "Pope Francis and the Christological Dimensions of Solidarity in Catholic Social Teaching." *Theological Studies* 80, no. 1 (2019): 102-122.

Clarke, Amanda, Elizabeth Jane Hanson, and Helen Ross. "Seeing the Person Behind the Patient: Enhancing the Care of Older People Using a Biographical Approach." *Journal of Clinical Nursing* 12, no. 5 (2003): 697-706.

CNA Staff. "Following Trump's Halt to US Immigration, Bishops Call for Solidarity." *CNA*, April 24/ 5:13 pm MT 2020.

Coulter, Albert. "Dogmatic Constitution on the Church: A Response." In *The Documents of Vatican II: Introductions and Commentaries by Catholic Bishops and Experts, Responses by Protestant and Orthodox Scholars*, edited by Walter M Abbott, 102-106. New York: America Press Inc., 1966. Reprint, April 30, 2012.

Council Fathers of Vatican II. "Declaration on Religious Freedom (Dignitatis Humanae)." In *The Documents of Vatican II: Introductions and Commentaries by Catholic Bishops and Experts, Responses by Protestant and Orthodox Scholars*, edited by Walter M Abbott America Press Inc., 1966.

———. "Declaration on Religious Liberty (Dignitatis Humanae)." In *Vatican Council II: Constitutions, Decrees, Declarations: The Basic Sixteen Documents. A Completely Revised Translation in Inclusive Language*, edited by Austin Flannery Collegeville, MN: Liturgical Press, 1996.

———. "Decree on the Apostolate of the Laity (Apostolicam Actuositatem)." edited by Walter M Abbott New York: America Press Inc., 1966.

———. "Decree on the Ministry and Life of Priests (Presbyterorum Ordinis)." edited by Walter M Abbott New York: America Press Inc., 1966.

———. *The Documents of Vatican II: Introductions and Commentaries by Catholic Bishops and Experts, Responses by Protestant and Orthodox Scholars*. April 30, 2012, New York: America Press Inc., 1966.

———. "Dogmatic Constitution on the Church (Lumen Gentium)." In *Vatican Council II: Constitutions, Decrees, Declarations: The Basic Sixteen Documents. A Completely Revised Translation in Inclusive Language*, edited by Austin Flannery, OP Collegeville, MN: Liturgical Press, 1996.

———. "Dogmatic Constitution on the Church (Lumen Gentium)." In *The Documents of Vatican II: Introductions and Commentaries by Catholic Bishops and Experts, Responses by Protestant and Orthodox Scholars*, edited by Walter M Abbott New York: America Press Inc., 1966.

———. "Message to Humanity." In *The Documents of Vatican II: Introductions and Commentaries by Catholic Bishops and Experts, Responses by Protestant and Orthodox Scholars*, edited by Walter M Abbott New York: America Press Inc., 1966.

———. "Pastoral Constitution on the Church in the Modern World (Gaudium Et Spes)." In *The Documents of Vatican II: Introductions and Commentaries by Catholic Bishops and Experts, Responses by Protestant and Orthodox Scholars*, edited by Walter M Abbott New York: America Press Inc., 1966.

———. "Pastoral Constitution on the Church in the Modern World (Gaudium Et Spes)." In *Vatican Council II: Constitutions, Decrees, Declarations: The Basic Sixteen Documents. A Completely Revised Translation in Inclusive Language*, edited by Austin Flannery Collegeville, MN: Liturgical Press, 1996.

Cribbin, Fr. Thomas R. "Born Free????". *NAMR Quarterly Publication* 6, no. 3 (Fall 1975): 21-22.

Cunningham, F.L.B. *The Christian Life*. Eugene, OR: Wipf & Stock Publishers, 2010. Google Books. <https://books.google.com/books?id=d3VMAwAAQBAJ>.

Cushing, Richard Cardinal. "Letter to Fr. Matthew Pesaniello." *NAMR Quarterly Publication* 1, no. 1 (September 1968): 1.

D Almeida, Michelle, RF Hume, Anthony Lathrop, Adaku Njoku, and Byron C Calhoun. "Perinatal Hospice: Family-Centered Care of the Fetus with a Lethal Condition." *Journal of American physicians and surgeons* 11, no. 2 (2006): 52.

David, Eric John Ramos, and Annie O. Derthick. "What Is Internalized Oppression, and So What?" In *Internalized Oppression: The Psychology of Marginalized Groups*, edited by Eric John Ramos David New York: Springer Publishing Company, 2013.

Davis, Cassandra J., and Jolene M. Thibedeau Boyd. "Stop Making It Weird: Why I'm Not Clapping." *Journal of Vocational Rehabilitation* 46 (2017): 321-325.

de Dreuille, Mayeul, O.S.B. *The Rule of Saint Benedict: A Commentary in Light of World Ascetic Traditions*. Mahwah, NJ: Paulist Press, 2002.

de Vogüé, Adalbert *The Rule of Saint Benedict: A Doctrinal and Spiritual Commentary*. Translated by John Baptist Hasbrouck. Cistercian Studies Series. Kalamazoo, Michigan: Cistercian Publications, 1983. La Règle de saint Benoît, VII, commentaire doctrinal et spirituel.

DeLeo, John. "Conference Report." *NAMR Quarterly Publication* 3, no. 1 (Spring 1971): 7-15.

Dickens, Charles. *A Christmas Carol*. August 11, 2004, London: Chapman & Hall, 1843. <https://www.gutenberg.org/files/46/46-h/46-h.htm>.

Dickerman, Dick. "A Parent of a Mentally Retarded Child Tells Why and How." *NAMR Quarterly Publication* 1, no. 1 (September 1968): 16-17.

Disability, Institute on Theology and. "Unpublished, Bill Sharing Stories During Conference Conversation." edited by Bill Gaventa: Holland, MI, 2016.

- Doak, Mary. "Sex, Race, and Culture: Constructing Theological Anthropology for the Twenty-First Century." *Theological Studies* 80, no. 3 (2019): 508-529.
- Doehring, Carrie. *The Practice of Pastoral Care: A Postmodern Approach*. Louisville, KY: Westminster John Knox Press, 2015. Kindle Book.
- Downes, Sister Rosemary, C.I.J. "The President's Views." *NAMR Quarterly Publication* 10, no. 3 (Fall 1979): 1.
- Dubois, Jacques, OSB. "The Laybrothers' Life in the Twelfth Century: A Form of Lay Monasticism." *Cistercian Studies Quarterly* 7, no. 3 (1972): 161-213.
- Duffner, Fr. P.A., O.P. "Guest Editorial: A Good Stewardship." *NAMR Quarterly Publication* 2, no. 3 (March 1970).
- Dunn, Patricia A, and Jacob Stratman. "Disabling Assumptions:" Overcoming": Analyzing Motivations in Shark Girl and the Running Dream." *The English Journal* 104, no. 4 (2015): 103-105.
- Dupuis, Jacques. *Who Do You Say I Am?: Introduction to Christology*. Orbis, 1994.
- Dybad, Rosemary. "Parish Awareness – International Developments and Voluntary Associations for the Mentally Retarded." *NAMR Quarterly Publication* 10, no. 3 (Fall 1979): 3.
- Elsa. "What Message Do Tim Tebow's Special Needs Proms Really Send?" In *All Abilities. Limitless Possibilities.*: Easterseals, undated.
- Fee, Gordon D. *The First Epistle to the Corinthians*. New International Commentary on the New Testament. Grand Rapids, MI: Wm. B. Eerdmans Publishing, 1987.
- Fitz-Gibbon, Jorge "Nj Family Furious after Catholic Church Denies Autistic Son First Communion." *New York Post*, February 27, 3:53pm, updated 2020.
- Fitzmyer, Joseph A. "Pauline Theology." In *The New Jerome Biblical Commentary*, edited by Raymond Edward Brown, Joseph A Fitzmyer and Roland Edmund Murphy, 1382-1416. Upper Saddle River, NJ: Prentice Hall, 1968.
- Flynn, Robert J. "A Conversation About Wolf Wolfensberger." edited by Anne Masters. telephone: conversation with author, 5/9/2020.
- Ford, Michael. *Wounded Prophet: A Portrait of Henri J. M. Nouwen*. New Yor: Doubleday, 2001.
- Fry, Timothy, OSB, ed. *RB 1980: The Rule of St. Benedict in Latin and English with Notes*. Collegeville, MN: Liturgical Press, 1981.

Gadoua, Renée K. "Auxiliary Bishop Thomas J. Costello Dies at 89." *The Catholic Sun*, 2019.

Gaillardetz, Richard R. *By What Authority?: A Primer on Scripture, the Magisterium, and the Sense of the Faithful*. Liturgical Press, 2003.

Gardner, Gregg E. *The Origins of Organized Charity in Rabbinic Judaism*. New York: Cambridge University Press, 2015.

Gaventa, Bill, Wesley Allen, Harold L Kleinert, and Erik W Carter. "Putting Faith to Work: The Call and Opportunity for Faith Communities to Transform the Lives of People with Disabilities and Their Communities." Kentucky, LA: Vanderbilt Kennedy Center, UCEDD, 2014.

Gengras, Fr. Joseph C. "Just Five Words." *NAMR Quarterly Publication* 3, no. 1 (Spring, 1971 1971): 4-5.

Giangrave, Claire. "Tim Tebow and the Vatican Join Forces to Give Disabled an Epic Prom Night." *CNA*, 2/7 2020.

Goodley, Dan. *Disability Studies: An Interdisciplinary Introduction*. Los Angeles: Sage, 2017.

Google Search. "Pope Francis, 'on the Margins'." Google
https://www.google.com/search?q=pope+francis%2C+%22on+the+margins%22&rlz=1C5CHFA_enUS747US747&oq=pope+francis%2C+%22on+the+margins%22&aqs=chrome..69i57.6682j0j7&sourceid=chrome&ie=UTF-8; .

———. "USCCB, 'on the Margins'." Google
https://www.google.com/search?q=USCCB%2C+%22on+the+margins%22&rlz=1C5CHFA_enUS747US747&oq=USCCB%2C+%22on+the+margins%22&aqs=chrome..69i57.6908j0j8&sourceid=chrome&ie=UTF-8.

Gregory of Nyssa. "On the Love of the Poor: 2 ".

Greig, Jason. "Striving Towards Dependence." *Anabaptist Witness* (2014).

Greig, JFR. "The Disarmed Community: Reflecting on the Possibility of a Peace Ecclesiology in the Light of L'arche." (2018).

Haight, Roger, SJ. *Christian Community in History* hardcover ed. Vol. Historical Ecclesiology New York, London: Continuum, 2004.

Handicapped, New York State Advisory Committee on Pastoral Ministry to the. "The Sacraments." 3, undated.

- Harrington, Daniel J, S.J. "The Gospel According to Mark." Chap. 41 In *The New Jerome Biblical Commentary*, edited by Raymond Edward Brown, Joseph A Fitzmyer and Roland Edmund Murphy, 596-629. Upper Saddle River, NJ: Prentice Hall, 1968.
- Harrington, Sister Mary Therese, S.H. "A Community of Believing People." *NAMR Quarterly Publication* 4, no. 2 (Summer 1972): 16-17.
- Harrington, Sister Mary Therese, S.H. . "President Views." *NAMR Quarterly Publication* 6, no. 1 (Spring 1975 1975).
- Harris Interactive. "2004 National Organization on Disability/Harris Survey of Americans with Disabilities." In *The National Organization on Disability*, 2004.
- . "The ADA, 20 Years Later." In *Survey of Americans with disabilities*, 27. New York: National Organization on Disability and Kessler Foundation, 2010.
- Hayes, Katherine M. "'The Major Prophets, Lamentations, and Baruch'." In *The Catholic Study Bible: The New American Bible: Revised Edition*, edited by Donald Senior; John J. Collins; Mary Ann Getty Oxford University Press, USA, 1991.
- Henley, Ariel. "We Don't Need Events Specifically for Disabled People." Having a prom for disabled people only is just as bad as 'separate but equal.' Vice, 2018.
- Himes, Michael J., SJ, and Kenneth R. OFM Himes. *Fullness of Faith: The Public Significance of Theology*. Mahwah, NJ: Paulist Press, 1993.
- Holman, Susan R. "Three Sermons." Translated by Susan R Holman. Chap. Appendix In *The Hungry Are Dying: Beggars and Bishops in Roman Cappadocia*. Oxford: Oxford University Press, 2001. Reprint, November 2003.
- Irwin, Kevin W. *Context and Text: A Method for Liturgical Theology*. Collegeville, MN: Liturgical Press, 1994.
- Johnson, Elizabeth A. *Women, Earth, and Creator Spirit*. The Madeleva Lecture in Spirituality. Edited by Notre Dame Saint Mary's College. Vol. 1993, Mahway, NJ,: Paulist Press, 1993.
- Johnstone, David. *An Introduction to Disability Studies, Second Edition*. 2005, Great Britain: Routledge, 2001.
- Karris, Robert J., O. F. M. "The Gospel According to Luke." Chap. 43 In *The New Jerome Biblical Commentary*, edited by Raymond Edward Brown, Joseph A Fitzmyer and Roland Edmund Murphy, 675-721. Upper Saddle River, NJ: Prentice Hall, 1968.

- Kieran, Rev. Richard A. . "Guidelines for the Pastoral Care of the Mentally Retarded." *NAMR Quarterly Publication* 1, no. December (1968): 5-8.
- Kirkpatrick, James D, and Wendy Kayser Kirkpatrick. *Kirkpatrick's Four Levels of Training Evaluation*. Alexandria, VA: ATD Press, 2016.
- Kristoffersen, Gugu. "Life Story Work: An Important, but Overlooked, Instrument." *Mental retardation* 42, no. 1 (2004): 70-76.
- L'Arche International. "Who We Are." L'Arche USA, <https://www.larcheusa.org/who-we-are/larche-international-2/>.
- LaCorte, Daniel M. "The Expositio and Monastic Reform at Cîteaux." Translated by David Barry, OSB. In *Commentary on the Rule of Saint Benedict, Smaragdus of Saint-Mihiel* 9-24. Kalamazoo, MI: Cistercian Publications, 2007.
- Lampe, Barbara J. "The Story of the National Apostolate for Inclusion Ministry." *Journal of Religion, Disability & Health* 10, no. 1-2 (2006/05/31 2006): 55-74.
- LaVerdiere, Eugene, S.S.S. "The Beginning of the Gospel of Jesus Christ with Eugene Laverdiere, Class Discussion." Paper presented at the College of Saint Elizabeth Summer Institute, College of Saint Elizabeth Convent Station, NJ, Summer 2003.
- . *The Beginning of the Gospel: Introducing the Gospel According to Mark*. Vol. 2, Collegeville, MN: Liturgical Press, 1999.
- Lawrence Cardinal Shehan. "Introduction." In *The Documents of Vatican II: Introductions and Commentaries by Catholic Bishops and Experts, Responses by Protestant and Orthodox Scholars*, edited by Walter M AbbottAmerica Press Inc., 1966.
- Lebbert, Dolores. "R.E.A.C.H.: Religious Education and Activities for the Community Handicapped." *NAMR Quarterly Publication* 6, no. 3 (Fall 1975 1975): 12-13.
- Lebel, Fr. Robert Roger, S.J. "Guest Editorial: A Proposal." *NAMR Quarterly Publication* 9, no. 1 (Spring 1978 1978).
- Lemay, Raymond. "Social Role Valorization Insights into the Social Integration Conundrum." *Mental Retardation* 44, no. 1 (2006): 1-12.
- Living Fully Team. "Statement and Charter from Living Fully 2016: Disability, Culture and Faith: A Celebration." [In English]. *Culture e Fede, Pontificium Consilium de Cultura, CIVITAS VATICANA* xxiv, no. 3 (December, 2016 2016): 208-218.
- LoBianco, Msgr. Francis R., PhD. "The Spiritual Equality of All God's Children." *NAMR Quarterly Publication* 1, no. 1 (September 1968): 6-9.

- Louwagie, Pam, and Curt Brown. "Accommodating Autism: Where's the Fine Line." *Star Tribune*, April 6, 2011 2011.
- Masters, Anne. "All Are Welcome: A Call for Greater Recognition and Participation of Persons with Disabilities in the Church." *New Jersey Catholic*, June 2018, 14-19.
- . *Pastoral Ministry with Persons with Disabilities Parish Resource Guide*. Newark, NJ: The Advocate, 2013.
- Matthews, Pia. "Participation and the Profoundly Disabled: "Being" Engaged—a Theological Approach." *Journal of Religion, Disability & Health* 17, no. 4 (2013): 426-438.
- McBrien, Fr. Richard. "The Faith to Be Communicated, Author's Notes." In *The Spiritual Equality of All God's Children*, 4. Passionist Monastery, West Hartford CT: University of Notre Dame Archives, 1970.
- McLaughlin, Colleen, Richard Byers, and RP Vaughn. "Responding to Bullying among Children with Special Educational Needs and/or Disabilities." 78. London, UK: University of Cambridge 2010.
- Meininger, Herman P. "Narrating, Writing, Reading: Life Story Work as an Aid to (Self) Advocacy." *British Journal of Learning Disabilities* 34, no. 3 (2006): 181-188.
- Meinold, Krauss. *Karl Rahner: I Remember, an Autobiographical Interview with Meinold Krauss*. Edited by Harvey D. Egan, S.J.: Crossroad, 1985.
- Meyer, Linda. "Inclusion for Individuals with ASD Throughout the Lifespan." edited by COSAC. Caldwell College, West Caldwell, NJ, 2006.
- Miller, Sonya R. "A Curriculum Focused on Informed Empathy Improves Attitudes toward Persons with Disabilities." *Perspectives on Medical Education* 2, no. 3 (2013): 114-125.
- Minnesota Governor's Council on Developmental Disabilities. "The Fight for Civil Rights for People with Disabilities." Minnesota Governor's Council on Developmental Disabilities, disabilityjustice.org.
- Mollat, Michel. *The Poor in the Middle Ages: An Essay in Social History*. Yale University Press, 1986.
- Moltmann, Jürgen. *The Spirit of Life: A Universal Affirmation*. Fortress Press, 1992. Century Religious Thought: Volume I, Christianity.
- Morris, Charles. *American Catholic: The Saints and Sinners Who Built America's Most Powerful Church*. New York: Vintage, 2011.

Murphy-O'Connor, Jerome. *St. Paul's Corinth: Texts and Archaeology*. Third Revised and Expanded Edition ed. Collegeville, MN: Liturgical Press, 2002.

Murphy-O'Connor, Jerome "The First Letter to the Corinthians." In *The New Jerome Biblical Commentary*, edited by Raymond Edward Brown, Joseph A Fitzmyer and Roland Edmund Murphy. Upper Saddle River, NJ: Prentice Hall, 1968.

Murray, John Courtney. *The Problem of Religious Freedom*. Newman Press, 1965.

———. "Religious Freedom." In *The Documents of Vatican II: Introductions and Commentaries by Catholic Bishops and Experts, Responses by Protestant and Orthodox Scholars*, edited by Walter M Abbott New York: America Press Inc., 1966.

NAMR Board. "National Apostolate for the Mentally Retarded Constitution Excerpts." *NAMR Quarterly Publication*, no. 1 (September 1968): 1.

———. "Toward a National Catechetical Directory Part 1." *NAMR Quarterly Publication* 5, no. 2 (Summer 1974): 4.

National Geographic. "Solar Eclipse 101." National Geographic, <https://youtu.be/cxrLRbkOwKs>.

NCCB. "Proposed Action Item Amendment: Pastoral Statement on Handicapped People." 1978.

———. "Statement on National Office for the Handicapped." 2, 1982.

NCPD Archives. "Executive Board and Board of Directors Meeting Notes."

Neuville, Elizabeth, ed. *An Introduction to Social Role Valorization: A Framework for Assisting People to Have Full, Rich and Meaningful Lives. Resource Manual for a Comprehensive SRV Workshop*. Harrisburg, PA: The Keystone Institute, 2017.

Nirje, Bengt. "The Basis and Logic of the Normalization Principle." *Australia and New Zealand Journal of Developmental Disabilities* 11, no. 2 (1985): 65-68.

Nouwen, Henri JM. *Adam: God's Beloved*. Maryknoll, NY: Orbis Books, 2012. electronic book.

O'Collins, Gerald. *Retrieving Fundamental Theology: The Three Styles of Contemporary Theology*. Mahwah, NJ: Paulist Press, 1993.

O'Hanlon, Elizabeth E. "Religion and Disability: The Experiences of Families of Children with Special Needs." *Journal of Religion, Disability & Health* 17, no. 1 (2013): 42-61.

Parmenter, Trevor R. "Inclusion and Quality of Life: Are We There Yet?". *International Public Health Journal* 6, no. 4 (2014): 413-428.

Pastoral Ministry with Persons with Disabilities. "Inclusive Family Mass Schedule." Archdiocese of Newark,
[https://www.rcan.org/sites/default/files/files/IFM%20Sept%202019-June%202020%20OLL%20not%20confirmed\(1\).pdf](https://www.rcan.org/sites/default/files/files/IFM%20Sept%202019-June%202020%20OLL%20not%20confirmed(1).pdf).

Patka, Mazna, and Katherine E McDonald. "Intellectual Disability and Faith Communities: Perspectives of Catholic Religious Leaders." *Disability & Society* 30, no. 8 (2015): 1241-1258.

Perkins, Pheme. "The Gospel According to John." Chap. 61 In *The New Jerome Biblical Commentary*, edited by Raymond Edward Brown, Joseph A Fitzmyer and Roland Edmund Murphy, 942-984. Upper Saddle River, NJ: Prentice Hall, 1968.

Perry, David. "'Amoris Laetitia' Reflects Narrow View of Disabled Persons." CRUX,
<http://www.cruxnow.com/church/2016/04/12/amoris-laetitia-reflects-narrow-view-of-disabled-persons>.

———. "Pope Francis Needs to Do More Than Kiss the Disabled." CRUX,
<https://cruxnow.com/vatican/2016/06/14/pope-francis-needs-kiss-disabled>.

Perske, Bob. "Some Hints toward Developing Small Core Youth Groups." *NAMR Quarterly Publication* 6, no. 2 (Summer 1975 1975): 17.

Perske, Robert. "The Dignity of Risk and the Mentally Retarded." (1972): 6.

Pesaniello, Rev. Matthew M. . "The Role of Administration by the Church in the Special Education Field." *NAMR Quarterly Publication* 1, no. DECEMBER (1968): 1-2.

———. "Why a "National Apostolate for the Mentally Retarded"?" *NAMR Quarterly Publication* 1, no. 1 (September 1968): 3-4.

Petersen, Kris, and Patrick Henry. "Youth Core Groups: To Bring People Closer." *NAMR Quarterly Publication* 6, no. 1 (Fall 1975 1975): 7-8, 24.

Petersilia, Joan R. "Crime Victims with Developmental Disabilities: A Review Essay." *Criminal Justice and Behavior* 28, no. 6 (2001): 655-694.

Pontifical Council for Justice and Peace. "Compendium of the Social Doctrine of the Church." Washington, DC: Libreria Editrice Vaticana, 2004. Reprint, 2005.

Pontifical Council for the Promotion of the New Evangelization. "Directory for Catechesis." Washington, D.C.: USCCB, 2020.

Pope Benedict XVI. *Caritas in Veritate (Charity in Truth)*. Washington, D. C.: United States Conference of Catholic Bishops, Vatican City: Libreria Editrice Vaticana, (2009) 2011. e-book.

———. "Sacramentum Caritatis." Vatican: Libreria Editrice Vaticana, 2007.

Pope Francis. "Address for the 25th Anniversary of the Concilio Episcopale Italiana: Disability Ministry and Catechesis." In *Toscana Oggi.it*. Rome, 2016.

———. "Address of His Holiness Pope Francis to Participants in the Conference Organized by the Pontifical Council for Promoting New Evangelization." Vatican Libreria Editrice Vaticana, October 21, 2017.

———. *Amoris Laetitia (the Joy of Love)*. Beacon Publishing, Libreria Editrice Vaticana, 2016.

———. "Evangelii Gaudium (Joy of the Gospel)." Vatican City: Libreria Editrice Vaticana, 2013.

———. "Gaudete Et Exsultate (Rejoice and Be Glad)." Vatican City: Libreria Editrice Vaticana, 2018.

———. *Laudato Si (on Care for Our Common Home)*. Brooklyn: Melville House Publishing, Libreria Editrice Vaticana, 2015.

———. "Looking for Mercy - Bull of Indiction of the Extraordinary Jubilee of Mercy." Vatican: Libreria Editrice Vaticana, 2015.

———. "Tweet-People with Disabilities Are a Gift."
<https://twitter.com/pontifex/status/718710082406473728>.

Pope John Paul II. "Homily, Jubilee of the Disabled." Vatican: Libreria Editrice Vaticana, 2000.

———. "Laborem Exercens (through Work), Encyclical for 90th Anniversary of Rerum Novarum ". Vatican: Libreria Editrice Vaticana, 1981.

———. "Mane Nobiscum Domine (Stay with Us Lord), Apostolic Letter for Year of the Eucharist." Vatican City: Vatican Publishing House, 2004.

———. "Message of John Paul II on the Occasion of the International Symposium on the Dignity and Rights of the Mentally Disabled Person." Vatican Libreria Editrice Vaticana, 2004.

Pope John XXIII. "Pacem in Terris (Peace on Earth)." Vatican City: Libreria Editrice Vaticana, 1963.

- . "Pope John Convoques the Council." In *The Documents of Vatican II: Introductions and Commentaries by Catholic Bishops and Experts, Responses by Protestant and Orthodox Scholars*, edited by Walter M Abbott New York: America Press Inc., 1966.
- . "Pope John's Opening Speech to the Council." In *The Documents of Vatican II: Introductions and Commentaries by Catholic Bishops and Experts, Responses by Protestant and Orthodox Scholars*, edited by Walter M Abbott New York: America Press Inc., 1966.
- Pope Paul VI. "Evangelii Nuntiandi (Proclaiming the Gospel)." Vatican City: Libreria Editrice Vaticana, 1975.
- Race, David, Kathy Boxall, and Iain Carson. "Towards a Dialogue for Practice: Reconciling Social Role Valorization and the Social Model of Disability." *Disability & Society* 20, no. 5 (2005): 507-521.
- Rahner, Karl. "The Body in the Order of Salvation." *Theological investigations* 17 (1981): 71-89.
- . "Christology Today?". *Theological investigations* 14 (1966): 24-38.
- . *The Love of Jesus and the Love of Neighbor*. Crossroad Publishing Company, 1983.
- . "Towards a Fundamental Theological Interpretation of Vatican II." *Theological studies* 40, no. 4 (1979): 716-727.
- Random House Unabridged Dictionary Online. "Dictionary.Com." Dictionary.com, <https://www.dictionary.com>.
- Rankin, Jenny. "What Is Narrative?". *Concrescence: The Australasian Journal of Process Thought* 3 (2002): 12.
- Reinders, Hans S. *Disability, Providence, and Ethics: Bridging Gaps, Transforming Lives*. Baylor University Press, 2014.
- . *Receiving the Gift of Friendship*. B002B54G91, Grand Rapids: Wm. B. Eerdmans Publishing, 2008.
- . *Receiving the Gift of Friendship*. Profound Disability, Theological Anthropology, and Ethics. Grand Rapids: Wm. B. Eerdmans Publishing, 2008.
- . "Spiritual Encounter: The Power of Inclusion and Friendship." *Journal of Religion, Disability & Health* 15, no. 4 (2011): 431-436.

- . "Understanding Humanity and Disability: Probing an Ecological Perspective." *Studies in Christian Ethics* 26, no. 1 (2013): 37-49.
- . "What's Wrong with Charity? Considerations for a Modern Travesty of Christian Ethics." Translated by Hans Reinders. In *Say What's Up. Try Exploratory Ethics. Ceremony in Honor of Hans G. Ulrich*, edited by Gerard den Hertog, Stefan Heuser, Marco Hofheinz and Bernd Wannenwetsch, 135-160. Leipzig: Evangelical Publishing House, 2017.
- Reynolds, Thomas E. "Improvising Together: Christian Solidarity and Hospitality as Jazz Performance." *Journal of Ecumenical Studies* 43, no. 1 (2008).
- . "Invoking Deep Access: Disability Beyond Inclusion in the Church." *Dialog* 51, no. 3 (2012): 212-223.
- . "Theology and Disability: Changing the Conversation." *Journal of Religion, Disability & Health* 16, no. 1 (2012): 33-48.
- . *Vulnerable Communion: A Theology of Disability and Hospitality*. Grand Rapids, MI: Brazos Press, 2008. Kindle
- Rhee, Helen. *Loving the Poor, Saving the Rich: Wealth, Poverty, and Early Christian Formation*. Baker Books, 2012.
- Roos, Philip, and Brian M. McCann. "Major Trends in Mental Retardation." *International Journal of Mental Health* 6, no. 1 (1977): 3-20.
- Rucker, Philip. "'How Do You Stop These People?': Trump's Anti-Immigrant Rhetoric Looms over El Paso Massacre." *Washington Post*, August 4, 2019 5:04 p.m. 2019.
- Rynne, Xavier. *Vatican Council II*. 3rd ed. Maryknoll, NY: Orbis Books, 1996. 1999.
- Saint Augustine. *The City of God against the Pagans*. Cambridge: Cambridge University Press, 1998.
- Schalock, Robert L. , and Michael L Wehmeyer. "The Parent Movement: Late Modern Times: 1950 CE to 1989 CE." Chap. 8 In *The Story of Intellectual Disability: An Evolution of Meaning, Understanding, and Public Perception*, edited by Michael L. Wehmeyer, 187-232. Baltimore, London and Sydney: Brookes Publishing, 2013.
- Shakespeare, Tom. *Disability Rights and Wrongs Revisited*. New York Routledge, 2014.

Strong, James L L. D., S. T. D. *The Strongest Strong's Exhaustive Concordance of the Bible, Fully Revised and Corrected*. Edited by John R. III Kohlenberg and James A. Swanson. Grand Rapids, MI: Zondervan, 2001.

Swanson, Cindi. "I Came for the Juice Boxes and Stayed for the Soul Food." in person: conversation with author, April 2016.

Swinton, John. "From Inclusion to Belonging: A Practical Theology of Community, Disability and Humanness." *Journal of Religion, Disability & Health* 16, no. 2 (2012): 18.

Swinton, John, Harriet Mowat, and Susannah Baines. "Whose Story Am I? Redescribing Profound Intellectual Disability in the Kingdom of God." *Journal of Religion, Disability & Health* 15, no. 1 (2011): 5-19.

Synod of Bishops. "Working Document: Young People, the Faith and Vocational Discernment." The Vatican: Vatican, 2018.

The Boggs Center on Developmental Disabilities. "Employment Specialist Foundations Course." edited by Bethany Cox: Stanhope, NJ, Fall 2019.

The Keystone Institute. "An Introduction to Social Role Valorization: A Framework for Assisting People to Have Full, Rich and Meaningful Lives: A Comprehensive SRV Workshop." edited by Elizabeth Neuville. Harrisburg, PA, March 2018.

Thibedeau Boyd, Jolene M, and Cassandra J Beckman. "Stop Making It Weird 2.0: Imagining a Less-Weird World." *Journal of Vocational Rehabilitation* 50, no. 3 (2019): 301-305.

Thiselton, Anthony C. *The First Epistle to the Corinthians: A Commentary on the Greek Text*. Grand Rapids, MI, Cambridge, U.K.; Carlisle, Cumbria: Wm. B. Eerdmans Publishing; The Paternoster Press, 2000.

Thomas, Susan. "A Conversation About Wolf Wolfensberger." phone conversation: conversation with author, 5/12/2020.

———. "Historical Background and Evolution of Normalization-Related and Social Role Valorization-Related Training." In *A Quarter-Century of Normalization and Social Role Valorization: Evolution and Impact*, edited by Robert A. Flynn and Raymond Lemay, 353. Ottawa: University of Ottawa Press, 1999.

Thompson, Carlos. "From Longing to Belonging: Theological Education." In *Summer Institute on Theology and Disability 2019: From Longing to Belonging*. Hope College, Holland MI, 2019.

- Thompson, Rachel. "Using Life Story Work to Enhance Care: Rachel Thompson Describes How Staff Can Be Supported to Implement and Sustain Biographical Approaches with Clients." *Nursing older people* 23, no. 8 (2011): 16-21.
- Tyree, Milton S, Michael J Kendrick, and Sandra Block. "Strengthening the Role of the Employee: An Analysis of Supported Employment Using Social Role Valorization Theory." *Journal of Vocational Rehabilitation* 35, no. 3 (2011): 197-209.
- USCCB. "A Century of Social Change: A Common Heritage, a Continuing Challenge." Washington, DC: United States Conference of Catholic Bishops, 1990.
- . "Economic Justice for All: Catholic Social Teaching and the U.S. Economy." Washington, DC: United States Conference of Catholic Bishops, 1986. Reprint, 1997.
- . "Guidelines for Celebration of the Sacraments with Persons with Disabilities." Washington, D.C.: U.S. Catholic Conference, 1995.
- . "Guidelines for Celebration of the Sacraments with Persons with Disabilities Revised Edition." Washington, DC: USCCB, 2017.
- . *National Directory for Catechesis*. Washington, D.C.: USCCB, 2005.
- . "Pastoral Statement of the U.S. Catholic Bishops on Handicapped People." 7. Washington, DC: USCCB, 1978.
- . "Pastoral Statement of the U.S. Catholic Bishops on People with Disabilities." Washington, DC: USCCB, 1978. Reprint, 1989, Updated language.
- . "Pastoral Statement of the U.S. Catholic Bishops on Persons with Disabilities,." Washington, DC: USCCB, 1978. Reprint, 1998.
- . "Sharing Catholic Social Teaching: Challenges and Directions." Washington, DC: USCCB, 1998.
- Vanier, Jean. *Community and Growth*. Revised ed. New York: Paulist Press, 1989.
- . "Living Our Faith with the Retarded Person." *NAMR Quarterly Publication* 4, no. 2 (June 1972): 2-5, 15.
- Vatican News. "Synodus Episcoporum Bulletin Xi Ordinary General Assembly." Vatican: Vatican News Service, 2005.
- Walsh, Mary Beth "Autism, Culture, Church: From Disruption to Hope." In *Living Fully 2016: Celebration of Disability, Culture, Practice and Faith*. Rome, Italy: The Pontifical Council For Culture and The Kairos Forum, 2016.

Webmaster. "About Justin Canha." <http://justincanha.com/about>.

———. "Most Rev. Thomas J. Costello, Retired Auxiliary Bishop of Syracuse, Dies at Age 89." Diocese of Syracuse, <https://www.syracusediocese.org/news/most-rev-thomas-j-costello-retired-auxiliary-bishop-of-syracuse-dies-at-age-89/>.

Whaley, Kayla. "Disabled People Are People: A Message to the Pope." In *Telling your followers to view us as objects that exist for the edification of abled people, tells them we're less than human*, @Pontifex., edited by @PunkinOnWheels, 2016.

———. "Disabled People Are People: A Message to the Pope." In *The Pope tweeted about disabled people as gifts and opportunities for abled people. I responded. Then the pushback to my call out started*.

Disabled people are PEOPLE. Full stop. We are not "gifts" or "opportunities" to ~teach abled people about love~, edited by @PunkinOnWheels, 2016.

———. "Disabled People Are People: A Message to the Pope." self, <https://storify.com/PunkinOnWheels/disabled-people-are-people-a-message-to-the-pope>

Wickham, Parnel "Poverty and the Emergence of Charity: Intellectual Disability in the Middle Ages (500 CE to 1799 CE)." Chap. 3 In *The Story of Intellectual Disability: An Evolution of Meaning, Understanding, and Public Perception*, edited by Michael L. Wehmeyer, 47-62. Baltimore, London, Sydney: Paul H. Brookes Publishing Co., 2013.

Winsor, Tracy. "Prenatal Diagnosis and Considerations for Parent Advocacy around Prenatal Screening and Diagnostic Testing." In *A presentation for Social Workers*. location unknown: Be Not Afraid, 2017.

Wolfensberger, Wolf. "An Attempt to Gain a Better Understanding from a Christian Perspective of What "Mental Retardation" Is." *Journal of Religion, Disability & Health* 4, no. 2-3 (2001): 71-83.

———. "An Attempt toward a Theology of Social Integration of Devalued/Handicapped People." *Journal of Religion, Disability & Health* 4, no. 2-3 (2001): 49-70.

———. "A Brief Overview of Social Role Valorization." *Mental retardation* 38, no. 2 (2000): 105-123.

———. "A Contribution to the History of Normalization, with Primary Emphasis on the Establishment of Normalization in North America between 1967-19751." In *A Quarter-Century of Normalization and Social Role Valorization: Evolution and Impact*, edited by Robert J Flynn and Raymond Lemay, 3-69: University of Ottawa Press, 1999.

- . "The Good Life for Mentally Retarded Persons." *Journal of Religion, Disability & Health* 4, no. 2-3 (2001): 103-109.
- . "An "If This, Then That" Formulation of Decisions Related to Social Role Valorization as a Better Way of Interpreting It to People." *Intellectual and Developmental Disabilities* 49, no. 6 (2011): 456-462.
- . "The Most Urgent Issues Facing Us as Christians Concerned with Handicapped Persons Today." *Journal of Religion, Disability & Health* 4, no. 2-3 (2001): 91-102.
- . "The Normative Lack of Christian Communality in Local Congregations as the Central Obstacle to a Proper Relationship with Needy Members." *Journal of Religion, Disability & Health* 4, no. 2-3 (2001): 111-126.
- . *The Origin and Nature of Our Institutional Models*. Syracuse, ny: Human Policy Press, 1975.
- . "Our Moral Responsibilities as Providers or Utilizers of Human Services." *The Bulletin (Publication of the Christian Association for Psychological Studies)* (1980): 6-8.
- . "The Prophetic Voice and Presence of Mentally Retarded People in the World Today." *Journal of Religion, Disability & Health* 4, no. 2-3 (2001): 11-48.
- . "Response to the Responders." *Journal of Religion, Disability & Health* 4, no. 2-3 (2001/01/01 2001): 149-157.
- . "Social Role Valorization and, or Versus, "Empowerment"." *Mental Retardation* 40, no. 3 (2002): 252-258.
- . "Social Role Valorization: A Proposed New Term for the Principle of Normalization." *Intellectual and Developmental Disabilities* 49, no. 6 (1983): 435-440.
- Wolfensberger, Wolf , Bengt Nirje, Simon Olshansky, Robert Perske, and Philip Roos. *The Principle of Normalization in Human Services*. Toronto: National Institute on Mental Retardation, 1972. "The Principle of Normalization In Human Services" Books: Wolfensberger Collection. 1.
- Wolfensberger, Wolf, and Robert Kugel, eds. *Changing Patterns in Residential Services for the Mentally Retarded*. Washington, D.C.: The President's Committee on Mental Retardation, 1969.
- Wolfensberger, Wolf, Susan Thomas, and Guy Caruso. "Some of the Universal "Good Things of Life" Which the Implementation of Social Role Valorization Can Be

Expected to Make More Accessible to Devalued People." *International Social Role Valorization Journal* 2, no. 2 (Autumn 1996): 12-15.

World Health Organization. "Towards a Common Language for Functioning, Disability and Health: ICF. Geneva, Switzerland: World Health Organization." Retrieved 06/20/2012 from <http://www.who.int/classifications/icf/beginners/bg.pdf>, 2002.

World Health Organization, and The World Bank. "World Report on Disability." Geneva, Switzerland: WHO, 2011.

Zaki, Jamil. "Empathy: A Motivated Account." *Psychological bulletin* 140, no. 6 (2014): 1608-1634.

———. *The War for Kindness: Building Empathy in a Fractured World*. New York: Crown, 2019.

Zimmer, Ben. "Where Does Trump's 'Invasion' Rhetoric Come From?" *The Atlantic*, August 6 2019.